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ABSTRACT

This document reports on a survey of 309 Virginians with disabilities, of all ages, concerning first, the satisfaction with and need for services, and second, the current status of efforts to increase independence, community integration, and productivity among Virginians with developmental disabilities. Individual chapters address: the survey methodology, life roles, life supports and services, independence, community living and integration, and productivity. Services and supports related to financial welfare dominate perceptions of satisfaction and need. While satisfaction with direct services is generally high, satisfaction with supports is much lower, and Virginia's service system often fails to target its resources with appropriate differentiation across disability groups. Findings concerned with improving the quality of life for persons with developmental disabilities include the following: the unavailability of work is a major barrier to increasing productivity and quality of life for these people; the social support networks of most consumers are extremely limited; the commitment of caregivers and services to increased personal independence is limited by their vested interests; and many consumers remain isolated and limited in their "real world" involvement. The survey is appended. (DB)

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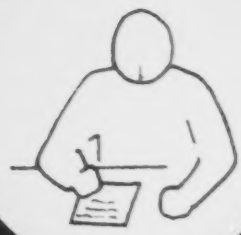

Appendix to
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# LIFE PATTERNS

## A REPORT ON LIFE AND SERVICE SATISFACTION OF VIRGINIANS WITH DEVELOPMENTAL DISABILITIES

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1990 REPORT
APPENDIX B

# LIFE PATTERNS

## A Report on Life and Service Satisfaction of Virginians with Developmental Disabilities

December, 1989

James S. Goalder
E. Davis Martin
Maureen J. Heck
Gerald L. Gandy
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TABLE OF CONTENTS


| | Page |
|---|---|
| **Acknowledgements** | i |
| **Executive Summary** | iv |
| **Chapter 1: Introduction** | 1 |
| Background | 1 |
| Content and Scope of the Study | 4 |
| Organization of the Report | 5 |
| A Note on Intent, Possibilities and Limitations | 10 |
| **Chapter 2: Methodology** | 13 |
| Sampling | 13 |
| Surveyor Selection | 14 |
| Interviewee Selection | 15 |
| Survey Process | 16 |
| Data Tabulation and Analysis | 17 |
| **Chapter 3: Life Roles** | 18 |
| Demographic Information | 19 |
| Functional Limitations of Survey Respondents | 26 |
| Life Roles in Youth and Adulthood | 37 |
| Summary on Life Roles | 55 |
| **Chapter 4: Life Supports and Services** | 60 |
| Case Coordination Services | 61 |
| Residential Services | 63 |
| Educational Services | 66 |
| Vocational and Other Adult Day Services | 70 |
| Health Services | 74 |
| Transportation Supports and Services | 75 |
| Individual Support Services | 78 |
| Caregiver Support Services | 90 |
| Satisfaction with Select Agencies and Programs | 99 |
| Summary on Life Supports and Services | 102 |
| **Chapter 5: Independence** | 110 |
| Independence and Living Arrangements | 110 |
| Independence in Community Settings | 112 |
| Independence in Educational Settings | 115 |
| Independence in Work Settings | 115 |
| Other Items Measuring Independence | 116 |
| Correlates with Independence | 118 |
| Summary on Independence | 122 |
| **Chapter 6: Community Living and Integration** | 125 |
| Integration into Family | 126 |
| Integration in Community | 134 |
| Integration in Educational Settings | 143 |
| Integration in Work Settings | 148 |
| Summary on Community Living and Integration | 148 |

Page

**Chapter 7: Productivity** ..... 151
Productivity and Living Arrangements ..... 152
Productivity in Community ..... 153
Productivity in Educational Settings ..... 156
Productivity in Work Settings ..... 160
Summary on Productivity ..... 168

**Chapter 8: Conclusions** ..... 172

**References** ..... 174
**Index** ..... 176
**Appendix** ..... 191

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muscle, and brain that carried this survey and report to their successful conclusion.

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## EXECUTIVE SUMMARY

### The Consumer Satisfaction Survey

The Consumer Empowerment Project, located in Virginia Commonwealth University's Department of Rehabilitation Counseling, conducted the Consumer Satisfaction Survey for the Planning Committee of the Board for Rights of the Disabled to determine (1) the satisfaction with and needs for services, and (2) the current status of efforts to increase independence, community integration, and productivity among Virginians with developmental disabilities. VCU's Community Services Assistance Center provided assistance related to data analysis. Surveyors and consumers to be interviewed were recommended by members of the Planning Committee and Board for Rights of the Disabled and by leaders of advocacy and consumer groups throughout the Commonwealth. Over 50 surveyors interviewed 309 Virginians with a wide range of disabilities grouped into four major categories: cognitive (e.g., mental retardation), physical (e.g., cerebral palsy), sensory (e.g., visual impairment), and mental illness (e.g., schizophrenia). A survey instrument developed by Temple University and the National Association of Developmental Disability Councils was used to collect data. All surveyors were either consumers or family members of consumers.

This summary is divided into two sections. The first focuses on priorities for expansion and improvement of services. The second section highlights the qualitative aspects of consumer lives and attempts to answer two questions: "What needs to be done to improve the quality of consumer's lives?" and "What are Virginia's current barriers to the full realization of independence, community integration, and productivity in the lives of Virginians with developmental disabilities?"

## Targets for Improving Services

1. Consumers with developmental disabilities are dissatisfied with sitting on the sidelines of life. They want the services and supports that will allow them to be active and integrated members of their communities.

   Consumers give high satisfaction ratings to all services aimed at increasing their community participation. Concurrently, they indicate a high level of need for services and supports such as community living assistance or training, self-help or support groups, and community support services. This finding is not surprising since our data indicate limited social community integration among members of our sample despite the fact that over 80% of adults rated community integration as important to their lives.

2. Services and supports related to financial welfare dominate perceptions of satisfaction and need.

The most consistent perceptions of satisfaction and need were related to financial welfare. Thus, high levels of need were indicated for income assistance, food assistance, financial management assistance, private health insurance, payment for medication, and payment or provision of medical equipment. Why is this area of assistance of such importance? Because having adequate income allows independence, community integration and productivity, values strongly endorsed by consumers. And because the ideal is so discrepant from reality - adult respondents to our survey had an estimated average annual projected earned income of $5600.

3. While satisfaction with Virginia's direct services is generally high, satisfaction with supports (that are often needed to use services effectively) is much lower.

Assistance to Virginia's consumers comes in two forms. Services (e.g., sheltered employment) are provided to mitigate the effects of a consumer's disability. In contrast, supports (e.g., on-site attendant) are provided to increase the effectiveness of the service and/or to contribute to the quality of life of the consumer. A decade ago, Virginia's service system offered virtually all persons in a category of disability

the same service mix regardless of a consumer's uniqueness. Today, there is a gradual trend toward designing a unique set of services and supports around the specific needs of a consumer. While this trend is commendable, there remains a consistent discrepancy between satisfaction with services and supports. For example, 72% of consumers receiving income assistance (i.e., SSI) are satisfied with that assistance, while only 55% are satisfied with the support that helps them make the most out of their income (i.e., financial management assistance). Educationally, satisfaction with regular school classes and career and professional education was 75% and 77%, respectively. In contrast, satisfaction with attendants and after-school tutors was 55% and 50%, respectively. Similar relationships held for services and supports for transportation and work. This pattern suggests a need for increased emphasis on improving supports in the service of major life roles and activities.

4. Virginia's service system often fails to target its resources with appropriate differentiation across disability groups.

Results from our survey suggest that the satisfaction with and needs for services are often different for different disability groups. For example,

there is a high need for transportation training for persons with physical disabilities, but not for other groups. Psychosocial rehabilitation is needed by persons with disabilities related to cognition and mental illness, but not other groups. On-site attendants are needed at work by many persons with physical and cognitive disabilities, but by few with sensory disabilities or mental illness. Fortunately, Virginia's service system is set up to provide different services for different disabilities. Unfortunately, it often fails to provide the services that are needed. When asked why they were not receiving needed services, a common response by consumers was "not eligible by type or degree of disability."

**Targets for Improving Quality of Life**

5. The unavailability of work is a major barrier to increasing productivity and quality of life for many persons with developmental disabilities.

Less than a third of adults in our sample worked full time, earning an annual projected income of just over $12,000. An additional 12% worked part time. Yet only 25% of our sample rated themselves as unable to work or retired. That means that 31%, almost a third, are available for work but are not working. Is working important? Eight of every ten consumers rated

productivity as important to them as a life value. Yet almost a third of the adult consumers felt generally unproductive. The practical implications of these statistics are stunning. Only 28% of adult consumers own their own home (compared to about 65% of 1980 households in Virginia). Over two-thirds of adult consumers reported continuing to live with relatives and over half described their primary caregiver as either a relative or service provider, strongly suggesting the daily implications of inadequate financial resources. Though a large percentage indicated a need for additional education, America's touted means for "lifting oneself up," a dominant theme for not obtaining such services was "service is too expensive to obtain."

6. <u>The social support networks of most consumers are extremely limited.</u>

Current psychological literature strongly suggests that social networks positively contribute to mental health and life satisfaction. They may also contribute to physical health. Yet involvement in social networks by most persons with developmental disabilities is quite limited. The neighborhood social contacts of both children and adults with developmental disabilities appear constricted when compared to those of peers without disabilities. Many life roles, which serve to

establish social networks (e.g., parent; worker; student) are either less available or more isolated from the mainstream for consumers. Only 23% of adults are members of consumer or advocacy groups despite a high satisfaction rating from persons who are members and a high level of stated need by consumers who are not members.

7. <u>The commitment of Virginia's primary caregivers and service system to the independence of persons with developmental disabilities is limited by the vested interests of the caregivers and service systems.</u>

Consumers show a very high level of independence in certain life activities (e.g., decorating one's room) but considerably less independence in other activities (e.g., handling personal finances). Lower levels of independence are often associated with the potential for inconvenience or liability on the part of caregivers or the service system. For example, only 24.1% of consumers whose primary caregiver was a service provider and 65.5% of consumers whose primary caregiver was a relative reported choosing their own jobs. Yet almost nine of ten (89.2%) consumers who indicated "self" as primary caregiver reported choosing their jobs. Assistance to increase level of independence in such activities as choosing one's own attendant or service provider and

handling personal finances is limited and sporadic for many.

8. <u>While childen and their parents are generally satisfied with their current service and family environments, this satisfaction often cloaks dependence, a potential barrier of importance to future life satisfaction</u>.

Children and adolescents are, for the most part, satisfied with their lives. Most live in loving and warm family settings and spend a great amount of their time in school. They are often given special assistance. For example, with 70% of youth in school, only 21% are in classrooms not providing special assistance. That we provide this for our children should comfort us. But how well do we ensure that children grow up believing they can be independent? Relatively few youth are members of consumer groups though over half of their parents have joined at least one group. On a majority of indices of independence, caregivers providing foster care allowed more freedom of choice to consumers than did either parents or institutional staff. These examples suggest a discrepancy between life values and reality. While eight of every ten consumers endorsed independence as an important life value, over half of these same consumers characterized themselves as dependent.

9. Many consumers remain isolated and limited in their involvement in "real world" roles and environments.

While children seem to be fairly satisfied with their lives, adults appear somewhat less so. How does such a change come about? Our results suggest that an answer may be found in considerations of life involvement. Children's lives revolve around the roles of child, student, and leisure person. In contrast, adults are traditionally engaged in additional roles. Many roles taken for granted by persons without disabilities are simply not available to persons with developmental disabilities. Seventy-nine percent of our sample of consumers had never married and, of those who had married, 40% had divorced (spouse role). Only 32% of adult consumers worked full time (worker role). Only 42% of adult consumers living in multi-family homes or institutions were allowed to choose their leisure activities on weekends and evenings (leisure role). The likelihood of having children if you have a developmental disability remains so remote that no questions about the needs of consumer-parents were included in the survey (parent role). Yet pleas for participation in the "real world" abounded on our survey. The issue is important. Over 80% of adult respondents indicated that integration into community was important to their lives.

## Preparing for Action

In this Executive Summary, we have attempted to describe the "forest, but not the trees." We believe that the image we have developed holds great promise for adding to the quality of life of Virginians with developmental disabilities.

As in any summary, the target image is broad in scope but lacks detail. That detail, the information to help in developing specific strategies for future work, is available in the body of the report. We encourage the reader of this summary to gain a better understanding of the substance of these target issues through reading the remainder of this report.

It is important to realize that dealing with the issues identified by this report is not only essential to enhance the quality of life for Virginians. Success is also realistic and attainable. It is time for Virginians to join together and begin.

## CHAPTER 1

## Introduction

This chapter is divided into four parts. The first, Background, describes the national imperatives and state decisions that culminated in this report. The second part, Content and Scope, describes the scope of the survey and reviews its general content. The third section, Organization of the Report, provides the background and rationale for the way in which the report is organized. Finally, the last part, a Note on Intent, Possibilities, and Limitations, focuses on some of the limitations of the study along with our hopes for how the results of this study will be used.

### Background

The Consumer Satisfaction Survey was developed in response to a Congressional mandate set forth in the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987 (Developmental Disabilities Act, Public Law 100-146, Section 122(f) (2) signed into law on October 29, 1987. This Legislation called for a national initiative to obtain consumer input into the planning process:

> Each State Planning Council shall conduct a review and analysis of the effectiveness of, and consumer satisfaction with...services...to all persons with developmental disabilities in the State. Such review and analysis shall be based upon a survey of a representative sample of persons with developmental disabilities receiving services...and their families, if appropriate.

This mandate required each state planning council in the 56 states and territories receiving Developmental Disabilities (DD) monies to collect these data, hold public forums in conjunction with interpretation of these data, and to develop a comprehensive, multifaceted report for submission to the governor and state legislature of each state or territory by January 1, 1990. The governor of each state is then to forward the report to the United States Secretary of Health and Human Services by January 15, 1990. At the national level, the aggregate data from the states will be submitted to the Congress by the Secretary on April 15, 1990.

Coordination of this national mandate was undertaken by the National Association of Developmental Disabilities Councils (NADDC). The Association's Work Group consisted of representatives from 15 states including Virginia. The NADDC began work in conjunction with the Temple University Affiliated Program (UAP) to address scientific sampling concerns regarding strategy, criteria and methods to approach this task. Their initial objectives were to determine:

- What is the best sampling approach to use given the constraints imposed by time lines and research methodology?
- What number of interviews need to be conducted in each state?
- What are the best available measurement approaches for satisfaction, independence, productivity, and integration? (Temple University, 1988)

It was considered highly desirable to have national comparability for the results of this survey. The new

mandate in the 1987 Act required a quality assessment at the national level. The reasoning behind this action was that future legislative action would need to be based on hard data regarding current strengths and weaknesses of the service network. Any improvements on current legislation would then be viewed as an enhancement. (Bradley, Ashbaugh, Harder, Stoddard, and Shea, 1984). This is a very important point since this is the first time that a comprehensive effort has been made to have consumers with developmental disabilities interviewed to assess their level of satisfaction with services which they are currently receiving.

Three definitive decisions were made at the national level.

- Each state's sample must be independent and representative.
- A minimum of 300 surveys would be administered in each state, with no disability category having fewer than 20 respondents.
- Consumer interviews would be carried out face-to-face.

The Consumer Satisfaction Survey is one part of a larger report known as The 1990 Report. The target population for the survey is a representative sampling of Virginia consumers with developmental disabilities who receive services from relevant federally-assisted programs. The aim of the survey is to determine the level of satisfaction of these persons with their lives and with the services they are receiving, to provide descriptive information on how persons with

disabilities live their lives, and to provide certain information of relevance to state policymakers.

In Virginia, this responsibility was undertaken by the Board for Rights of the Disabled (BRD) which is the State Planning Council for Developmental Disabilities in Virginia. Implementation of the Survey was delegated to the Consumer Empowerment Project, a DD grant-funded program, located at Virginia Commonwealth University.

## Content and Scope

The Survey is divided into six major components. These are: (a) demographics, (b) eligibility, (c) independence, (d) integration, (e) productivity, and (f) services and satisfaction. A copy of the Consumer Satisfaction Survey is presented in Appendix A.

**Eligibility**. This section contains information regarding the consumer's disability and eligibility for services in the seven areas contained in the Federal definition of developmental disabilities. Specific information is requested on level of assistance required for participation in the following activities: self-care, communicating, acquiring new skills, moving from place to place, life management, living on one's own, and paid work.

**Demographics**. This section contains information pertaining to the consumer's race, marital status, gender, school history, living situation, primary caregiver, and certain information related to affiliation with advocacy groups.

**Independence**. This section focuses on the consumer's ability to function independently in a broad range of daily tasks and living situations.

**Integration**. This section focuses on the extent to which the consumer takes part in common community activities and settings experienced by persons not having a disability. It also explores the degree to which persons with disabilities interact with persons not having a disability.

**Productivity**. This section focuses on the vocational aspects of a consumer's life. This includes employment history, income, fringe benefits, transportation to and from work, current financial situation, and unpaid productivity at home and in one's community.

**Services and Satisfaction**. This section focuses on the availability of services, satisfaction with those services, and the need for additional services. A subsection included questions on the consumer's quality of life, including satisfaction/happiness with living arrangements, neighborhood and its people, one's city, personal life, and work life.

## Organization of the Report

A key step in developing a useful state report out of the nationally-oriented Consumer Satisfaction Survey is to choose a meaningful organizational framework for presentation of state data.

One way of developing such a framework is to review different documents published by various state organizations and to compare the primary emphasis of these documents. Such an analysis was conducted using four recent reports: recommendations to the Governor for Virginia's most recent biennial report (Board for Rights of the Disabled, 1989), the Community Needs Survey for Persons with Developmental Disabilities (Community Services Assistance Center, 1987), Conference Report on Community Integration for Virginians with Disabilities, (Virginia Institute for Developmental

Disabilities, 1988), and the Survey of Virginians with Disabilities (Community Services Assistance Center, 1989). Results of the analysis are presented in Figure 1.

It is evident from this table that eight topical areas include the predominance of need determination and policy work in Virginia during this period. The eight areas are: employment, housing, education, transportation, health, statewide planning, community living/integration, and evaluation of the service system. A less obvious but second real trend can be noted. During this brief period, there has been an expansion beyond a focus on simple provision of services (e.g., employment; housing; transportation) toward on an emphasis on quality of life (e.g., community living; satisfaction with service agencies). Increasingly, consumer response to agency initiatives and support for certain quality of consumer life has been emphasized.

These changes are parallel to recent changes at the national level. A major change in federal legislation occurred in 1978 with the move away from a categorical definition of disability (e.g., mental retardation; epilepsy) toward a functional definition focused on level of severity regardless of disability category. There has also been an increased emphasis on community integration, a philosophy-driven movement suggesting that the quality of life of consumers will increase if they become an ongoing part of their community's life. That movement was reflected in the

**Figure 1**

**Major Content Emphasis of Select Virginia Statewide Efforts at Needs and Policy Analysis: 1988 - 1989**

| Recommendation from Biennial Report (1987) | Community Needs Survey (1987) | Community Integration Conference (1988) | Survey of Virginians with Disabilities (1989) |
|---|---|---|---|
| *Employment | *Needs for Service: Vocational | *Adults Working in Community | *Employment Status<br>*Training and Employment Program Experience |
| *Housing | *Needs for Service: Residential | *Adults Living in Community | *Living Arrangements<br>*Community Housing |
| *Education | *Needs for Service: Life Skills | *Adults Working in Community<br>*Educating Children and Youth | |
| *Transportation | *Needs for Service: Mobility/Adaptive Equipment | | |
| *Health | *Needs for Service: Medical | | *Source of Payment-Medical and Dental Care |
| *Statewide Planning | | | |
| *Community Living | *Needs for Service: Supportive/Assistance | *Adults Living in Community<br>*Supporting Families in Community | *Requirement for Mobility<br>*Requirement for Communication Devices |
| *Evaluation of the Service System | | | *Satisfaction with Service Agencies |

1978 legislation which emphasized three key areas for targeting of federal monies: consumer productivity, consumer independence, and integration of the consumer into the ongoing life of his or her community.

These national trends are reflected in the Consumer Satisfaction Survey. The Survey includes seven parts: eligibility/screening, demographics, services and satisfaction, independence, integration, productivity, and

supports/services and assistance needed. These survey categories are compared to the summative categories for content culled from the Virginia statewide efforts of 1987-1989 in Figure 2. The figure shows good coverage in the Consumer Satisfaction Survey for most data categories of importance to Virginia. The major exception is the Statewide Planning category.

The integration of these two categorical sets suggests a useful framework for organizing the report on the Consumer Satisfaction Survey for the most effective use by state officials. It suggests the importance of one set of categories that focus on function and around which, generally, the state service system is organized (e.g., transportation; housing; employment). A second set of categories focus on issues related to quality of life (e.g., community integration; independence).

There is a third set of categories of theoretical importance to Virginia. If Virginians are truly interested in the quality of life of persons with disabilities, there is a need to explore the nature of life involvement of such persons. This suggests the importance of life role as a means of understanding how persons with disabilities live their lives.

**Figure 2**

**Comparison of Categories of Analysis for Consumer Satisfaction Survey and Summative Categories for Virginia Statewide Efforts**

| Virginia State Need and Policy Emphasis Categories | Consumer Satisfaction Survey Categories |
|---|---|
| Employment | Productivity<br>Services and Satisfaction<br>Supports/Services/Assistance Needed<br>Independence |
| Housing | Integration<br>Independence<br>Services and Satisfaction<br>Supports/Services/Assistance Needed |
| Education | Services and Satisfaction<br>Supports/Services/Assistance Needed |
| Transportation | Services and Satisfaction<br>Supports/Services/Assistance Needed |
| Health | Independence<br>Services and Satisfaction<br>Supports/Services/Assistance Needed |
| Statewide Planning | |
| Community Living/ Integration | Independence<br>Integration<br>Services and Satisfaction<br>Supports/Services/Assistance Needed |
| Evaluation of the Service System | Services and Satisfaction |

Donald Super (1980) identified nine life roles that virtually all persons play during the course of their lives: child, student, leisure person, citizen, worker, spouse, homemaker, parent, and retiree. He further proposed that these roles are played out in four life theaters: the home, the community, the school, and the workplace. This organizational schema provides a useful framework for describing the lives of Virginians. Furthermore, it allows us to explore the practical aspects of the current goals of the disability movement within the context of roles and settings. Goals such as independence and integration are likely implemented quite differently in settings such as family, school, and community. For these reasons, an organizational schema that includes roles will be used for this report.

This proposed framework is presented in Figure 3. It should be noted that the outline appearing in Figure 3 is a theoretical one and will have data missing from some of the suggested categories.

## A Note on Intent, Possibilities, and Limitations

This is the first instance in which a national survey has been conducted on a face-to-face basis in which consumers with developmental disabilities have been directly asked for in-depth information that could impact directly on service delivery. This is an extremely important opportunity to

**Figure 3**

**Global Outline for Results Section of the Consumer Satisfaction Survey Report**

I. Life Roles
   - A. Child/Youth
   - B. Student
   - C. Leisure and Social Person
   - D. Worker
   - E. Citizen
   - F. Spouse
   - G. Parent
   - H. Homemaker
   - I. Retiree

II. Life Supports and Services
   - A. Housing
   - B. Transportation
   - C. Health
   - D. Other Individual Supports
   - E. Caregiver Supports

III. Independence

IV. Community Living/Integration

V. Productivity

VI. Conclusions

compare consumer perceptions of effectiveness of service delivery with the stated objectives and actions of delivery personnel.

Three main categories addressed in this survey are independence, productivity, and integration. These categories address the very basic issue of quality of life. The depth of information in this survey can provide new perspectives for service agendas.

Further, many existing surveys have used professional surveyors as the mainstay of their data collection. The Consumer Satisfaction Survey instead chose to use consumers with developmental disabilities or their family members to administer this survey. In addition to being an empowering undertaking for these surveyors, it is hoped that the accuracy of obtained information will be increased.

For the many individuals who have experienced the ebb and flow of services, this survey may be seen as a threat to what existing services they do have. The surveyors who worked on this survey were quite successful in interacting with the individuals they interviewed in the non-threatening environment of their residences. For many of the respondents, this 36-page survey was a time-consuming and frustrating experience, often taking up to two hours. The rapport between surveyor and respondent was the key to success and is a reflection of the commitment both parties felt to the importance of these data.

To Virginia, a real strength of this survey will be the fact that 56 states and territories have DD Councils that are completing this same format in the same time frame. Thus, Virginia will have a yardstick by which to measure service delivery and consumer satisfaction against national norms.

## CHAPTER 2

## Methodology

This chapter is divided into five parts: (a) sampling, (b) surveyor selection, (c) interviewee selection, (d) the survey process, and (e) tabulation and analysis of data.

### Sampling

Sampling with probability proportional to each disability group was chosen as the most feasible method for sampling Virginians with developmental disabilities. This means that the numbers of people with each type of disability in Virginia should be the same as the proportion in the national population as a whole. The Consumer Satisfaction Survey is not a strict random sample. Resources to do this type of extensive, scientific survey were not available. Standards used were those more consistent with modern market research (Temple University, 1988). This design is in keeping with recommendations from Temple University.

We chose to follow national age guidelines and disability categories developed by Temple University in the initial creation of the survey document. Quite simply this meant that we needed to survey 300 Virginians spread among four disability categories and several age ranges whose developmental disability began before the age of 22. Due to lack of availability of Virginia data, national prevalence

data were used and were culled from several published studies of disability prevalence (Boggs and Henney, 1978; Gollay, 1981). Age ranges and disability groups are represented in Table 1.

**Table 1**

**Suggested Population Groupings According to National Prevalence Rates**

| Disability Group | Age Groups | | | | |
|---|---|---|---|---|---|
| | 0-5 | 6-22 | 23-59 | 60+ | Total |
| Cognitive | 10 | 58 | 53 | 7 | 128 |
| Physical | 8 | 47 | 43 | 6 | 104 |
| Sensory | 3 | 21 | 19 | 4 | 47 |
| Emotional | 2 | 12 | 11 | 3 | 29 |
| TOTALS | 23 | 138 | 127 | 20 | 308 |

Surveyor Selection

It was decided that the use of consumers or their family members as surveyors for this survey would serve as an example of consumer empowerment and embody the very essence of the disability movement's philosophy. It was also our intent to assure that both the surveyors and individuals to be interviewed were a representative cross section of the Commonwealth.

Members of the Board for Rights of the Disabled and the Planning Committee of the Board (groups representing

consumers, families of consumers, State agencies and other vested interests) were asked to nominate potential surveyors.

Individuals nominated were contacted by mail and given materials explaining the survey and the task they were being asked to accomplish. Individuals interested in participating in the survey process were asked to attend one of four regional training sessions. Training sessions were held in Richmond, Lynchburg, Locust Grove, and Hampton. Excellent inter-agency cooperation was shown by the Virginia Community College System through the use of their board rooms for these training sessions.

Approximately 50 surveyors were trained and asked to conduct interviews on a face-to-face basis using the 36-page survey instrument. Face-to-face interviews were specified both because of the length of the survey document and the added benefit of surveyor presence to explain unfamiliar terms to respondents. The surveyors were asked to do pre-screening by telephone to ascertain that each potential interviewee met the eligibility requirements of the survey.

## Interviewee Selection

Consumer advocacy groups were targeted as a primary source of candidates to be interviewed. These groups were chosen because they were visible sources of consumers who were likely receiving at least some of the services with which the survey

was concerned. This survey was designed to assess consumer satisfaction with services provided by service agencies and does not address the needs of unserved populations. That issue is dealt with in another section of The 1990 Report.

Members of the Board for Rights of the Disabled and its Planning Committee were again asked for their assistance in identifying consumers who might be interviewed. Prospective interviewees were mailed descriptive information to ascertain their interest in participating. Individuals expressing interest were asked to complete a permission form granting surveyors permission to contact and interview them. More than 350 prospective interviewees were identified by this method. Persons to be interviewed were selected so as to match prevalence rates as noted in Table 1.

**The Survey Process**

An eleven-question screening procedure was carried out by telephone with each interviewee or their surrogate to make certain that the candidate was eligible for the survey. These questions were aimed at determining whether the disability was of a developmental nature, whether it occurred before age 22, and whether the individual required substantial help in at least three areas of daily activities. If it was determined that the consumer met these criteria, an appointment was made to complete the survey instrument.

## Tabulation and Analysis of Data

Upon completion, the survey forms were mailed by the surveyor back to the Consumer Empowerment Project at Virginia Commonwealth University in pre-paid envelopes where it was logged in and transmitted to the Rehabilitation Research and Training Center for data processing. Upon completion of the data processing, the Consumer Empowerment Project undertook the summation and the analysis of the data. In excess of 500 elements of data were generated by each of the 308 surveys. Table 2 shows the distribution of surveys across disability groups by age.

**Table 2**

**Distribution of Interviewees Across Disability Categories and Ages**

| | Age Groups | | | | |
|---|---|---|---|---|---|
| Disability Group | 0-5 | 6-22 | 23-59 | 60+ | Total |
| Cognitive | 13 | 50 | 53 | 8 | 124 |
| Physical | 18 | 36 | 39 | 5 | 98 |
| Sensory | 3 | 15 | 28 | 4 | 50 |
| Emotional | 5 | 16 | 14 | 2 | 37 |
| TOTALS | 39 | 117 | 134 | 19 | 309 |
| Institutionalized: 27 | | | | | |

## CHAPTER 3

## Life Roles

All of us at different times in our lives find ourselves doing certain things more, other things less. This involvement in different types of life activities defines our life roles. Our opportunities for and choices of life roles largely determine the nature and quality of our involvement with the world. The availability of life roles is related to age.

> People play a variety of roles as they mature, some of these roles beginning early in life, e.g., that of a child, and others beginning late in life, e.g., that of pensioner. At some life stages a person plays only one life role (e.g., that of child when still a neonate), and at others a number of roles, such as those of spouse, parent, homemaker, and worker when at the prime of life. (Super, 1980, p. 283)

Donald Super (1980) has identified nine roles common to most people during their lifetime. They are as follows, approximately in typical order of taking on the role: (a) child (including son and daughter), (b) student, (c) leisure person, (d) worker, (e) citizen, (f) spouse, (g) homemaker, (h) parent, and (i) pensioner.

Life roles are clearly related to the breadth and depth of one's participation in the world. They are important ways in which we define ourselves, molding an identify. Yet life roles are not equally available to all people. Some people face functional limitations that prohibit them from certain life roles. Others are kept from certain life roles through

prejudice, social or economic forces, or other mechanisms that may serve as a barrier to entry.

This chapter is divided into three sections. The first section presents demographic information such as gender and race to provide a better understanding of the survey's sample. The second section will present information on the functional limitations of our sample. For example, it will note the extent of assistance needed for communication versus assistance needed for mobility in our sample. This section will pave the way for data on the participation levels of persons with developmental disabilities in the major roles of life. The third section describes the nature of participation in life roles for persons with developmental disabilities for both youth and adults.

## Demographic Information

This section will be used to describe characteristics of the survey sample that may help in interpreting other survey results. From the perspective of age, 48.9% of our sample was below the age of twenty-two (i.e., youth) and 51.1% was above the age of 22 (i.e., adult). Table 3 breaks down these ages further across the life span. About a tenth (12.6%) of our respondents were pre-schoolers, aged 0-5. About a third more were traditional school age, between the ages of six and twenty. About another third (37.2%) were young adults from

ages 21 to 40. Another 11.3% were in middle age (ages 41-60) and 4.9% of our sample was over 60 years old.

**Table 3**

**Age of Sample Respondents by Dominant Life Function**

| Age | Number | Percent |
|---|---|---|
| 0-5 (Pre-School) | 39 | 12.6 |
| 6-20 (School) | 105 | 34.0 |
| 21-40 (Early Work) | 115 | 37.2 |
| 41-60 (Mature Work) | 35 | 11.3 |
| 61 and over (Preparation for retirement and retirement) | 15 | 4.9 |
| TOTAL | 309 | 100.0 |

From the perspective of gender, 60.9% of youth were male and 39.1% were female. For adults, 55.1% were male and 44.9% were female.

Racially, 87.4% of youth respondents were white. About one in ten (11.3%) were black and the remainder were Hispanic or classified as "other." For adults, 72.0% were white, 26.8% black and about 1% were Hispanic or classified as "other."

Finally, disabilities were sorted into four primary categories for reasons of data analysis. These categories and the disabilities sorted within them are given in Figure 4. It is important to note that not all disabilities are sorted into one of these categories. In order to maintain the maximum internal consistency for categories (crucial for

establishing real differences [e.g., differences in functional limitation] between the categories), disabilities that could not be clearly sorted into one of the four categories were

**Figure 4**

**Disabilities Associated with Each of Four Disability Categories**

| Disability Category | Disability |
|---|---|
| Physical | Cerebral Palsy<br>Cystic Fibrosis<br>Multiple Sclerosis<br>Muscular Dystrophy<br>Orthopedic Impairments<br>Spina Bifida<br>Spinal Cord Injury |
| Cognitive | Mental Retardation<br>Down's Syndrome |
| Sensory | Deafness and Severe Hearing Impairment<br>Blindness and Severe Visual Impairment<br>Severe Hearing and Visual Impairment |
| Mental Illness | Emotional<br>Schizophrenia<br>Depressive Illness |

omitted from this part of the analysis. They were included, however, in all other analyses. The most notable disability so treated was autism. For autism, independent analyses were conducted to compare persons with autism to persons with mental illness on the one hand and cognitive disabilities on the other. In each analysis, differences were such that the investigators chose not to sort autism into either of these

categories. Consequently, consumers with autism are not included in the categorical analyses of data but are included in all other analyses.

Table 4 shows the percent of our survey sample in each disability category for both youth and adults. For each, persons with cognitive disabilities form the largest category, between a third and a half of survey respondents. For the youth sample, about a fourth (27.0%) had physical disabilities and just over one in ten had a sensory disability (12.1%).

**Table 4**

**Number and Percent of Survey Respondents in Each Disability Category: Youth and Adults**

| Disability Category | Youth | | Adults | |
|---|---|---|---|---|
| | Number | Percent of Youth Sample | Number | Percent of Adult Sample |
| Physical | 38 | 27.0 | 29 | 17.3 |
| Cognitive | 64 | 45.7 | 65 | 38.7 |
| Sensory | 17 | 12.1 | 33 | 19.6 |
| Mental Illness | 5 | 3.5 | 14 | 8.3 |
| TOTAL | 124 | 88.3 | 141 | 83.9 |
| Other Disabilities | | 11.7 | | 16.1 |
| TOTAL | | 100.0 | | 100.0 |

The proportions for physical and sensory disabilities in adults were much more similar, about one in every five or six persons (17.3% - physical; 19.6% - sensory). Persons with mental illness made up the smallest category for both youth and adults (3.5% - youth; 8.3% - adults).

Tables 5 and 6 show specific disabilities as reported by respondents as primary and secondary, for youth and adults, respectively. The strongest first impression is the

**Table 5**

**Specific Disabilities Reported by Respondents as Primary or Secondary: Youth**

| Disability | Primary | | Secondary | |
|---|---|---|---|---|
| | Number | Percent | Number | Percent |
| None | 0 | 0.0 | 25 | 20.7 |
| Autism | 16 | 10.6 | 5 | 4.1 |
| Blindness | 7 | 4.6 | 5 | 4.1 |
| Cerebral Palsy | 24 | 15.9 | 10 | 8.3 |
| Deafness | 9 | 6.0 | 5 | 4.1 |
| Emotional | 5 | 3.3 | 3 | 2.5 |
| Epilepsy | 2 | 1.3 | 7 | 5.8 |
| Head Injury | 5 | 3.3 | 1 | 0.8 |
| Mental Retardation | 36 | 23.8 | 20 | 16.5 |
| Muscular Dystrophy | 3 | 2.0 | 0 | 0.0 |
| Orthopedic Impairment | 1 | 0.7 | 7 | 5.8 |
| Speech Impairment | 1 | 0.7 | 25 | 20.7 |
| Spina Bifida | 10 | 6.6 | 0 | 0.0 |
| Spinal Cord Injury | 0 | 0.0 | | |
| Deafness and Blindness | 1 | 0.7 | 0 | 0.0 |
| Other Neurological Impairment | 3 | 2.0 | 2 | 1.7 |
| Behavioral Problems | 0 | 0.0 | 1 | 0.8 |
| Other | 28 | 18.5 | 5 | 4.1 |

**Table 6**

**Specific Disability as Reported by Respondents as Primary or Secondary: Adults**

| Disability | Primary | | Secondary | |
|---|---|---|---|---|
| | Number | Percent | Number | Percent |
| None | 0 | 0.0 | 36 | 31.6 |
| Autism | 2 | 1.3 | 0 | 0.0 |
| Blindness | 20 | 12.7 | 12 | 10.5 |
| Cerebral Palsy | 19 | 12.0 | 6 | 5.2 |
| Deafness | 10 | 6.3 | 5 | 4.4 |
| Emotional | 14 | 8.9 | 8 | 7.0 |
| Epilepsy | 2 | 1.3 | 10 | 8.8 |
| Head Injury | 4 | 2.3 | 1 | 0.9 |
| Mental Retardation | 57 | 36.1 | 3 | 2.6 |
| Muscular Dystrophy | 2 | 1.3 | 0 | 0.0 |
| Orthopedic Impairment | 3 | 1.9 | 8 | 7.0 |
| | | | 0 | 0.0 |
| Speech Impairment | 0 | 0.0 | 18 | 15.8 |
| Spina Bifida | 1 | 0.6 | 0 | 0.0 |
| Spinal Cord Injury | 5 | 3.2 | | |
| Deafness and Blindness | 3 | 1.9 | 0 | 0.0 |
| Other Neurological Impairment | 5 | 3.2 | 1 | 0.9 |
| Behavioral Problems | 0 | 0.0 | 1 | 0.9 |
| Other | 11 | 7.0 | 5 | 4.4 |

proportion of persons with developmental disabilities that have multiple disabilities (i.e., 79.3% for youth; 68.4% for adults). This very high proportion for both youth and adults suggests that it is inappropriate in many cases for professionals to establish a single set of services in accordance with those commonly needed by persons with a particular disability and to offer them to all persons with that disability. Rather, it is essential to look at the unique limitations of each person and to design a service

array for maximum assistance. The very high proportion of persons with multiple disabilities has implications for Virginia's policymakers, as well. It suggests that combinations of disability (e.g., blindness and cerebral palsy; mental retardation and deafness; mental illness and orthopedic impairment) are quite common and are best dealt with by a closely coordinated progression of services with maximum flexibility. Yet, in Virginia, there are different agencies that are assigned to handle different disability categories (e.g., Department of Rehabilitative Services; Department of Mental Health, Mental Retardation, and Substance Abuse Services; Department for the Deaf and Hard of Hearing). Traditionally, multiple assignment of responsibility has often been associated with low levels of effectiveness in organizations due to difficulties of coordination. These data suggest that Virginia's current structure related to developmental disabilities may serve as a barrier for more Virginians than previously suspected. Additional research should be carried out in this important area to gain clarification on this important issue.

There was general agreement on which disabilities were likely to be seen as secondary ones. Both youth and adults indicated that speech impairment, cerebral palsy, epilepsy, and orthopedic impairment occurred in five percent or more of persons with secondary disabilities. For youth, mental retardation occurred as a secondary disability in 16.5% of the

sample. For adults, emotional disorders occurred as a secondary disability for 7.0% and blindness or visual impairment for 10.5% of respondents.

## Functional Limitations of Survey Respondents

To determine eligibility to participate in the Consumer Satisfaction Survey, a series of questions were asked of each potential survey respondent to determine the degree of assistance needed to accomplish several important life functions (e.g., communicate; move from place to place). In responding with "a lot", "a little", or "none", consumers indicated their functional limitations in tasks important to their day-to-day living. Because of differences in the nature of disabilities, differences in functional limitations would be expected across disability categories. The unique set of functional limitations for each disability category should be related somewhat to the life roles engaged in by persons with different types of disabilities.

Each survey respondent answered questions about his or her functional limitations in regards to each of the following life tasks: self-care (Table 7), communicating (Table 8), learning (Table 9), moving from place to place (Table 10), making decisions and managing his or her life (Table 11) living on his or her own (Table 12), and maintaining a source of income to support himself or herself (Table 13). Each of these functional areas will be reviewed below. An additional

section will profile each major disability category by type of primary functional limitation.

**Self-Care**. Self-care is a dominant issue for a majority of persons with physical disabilities. It also requires considerable assistance for a significant minority of persons

**Table 7**

**Needs for Assistance in Self-Care for Youth and Adults by Disability Category**

| Disability Category | Response | Youth | | Adults | |
|---|---|---|---|---|---|
| | | Number | Per-cent | Number | Per-cent |
| Physical | None | 4 | 10.5 | 11 | 37.9 |
| | A Little | 10 | 26.3 | 6 | 20.7 |
| | A Lot | 24 | 63.2 | 12 | 41.4 |
| Cognitive | None | 16 | 25.0 | 19 | 29.2 |
| | A Little | 25 | 39.1 | 27 | 41.6 |
| | A Lot | 23 | 35.9 | 19 | 29.2 |
| Sensory | None | 12 | 70.6 | 25 | 75.8 |
| | A Little | 3 | 17.7 | 6 | 18.2 |
| | A Lot | 2 | 11.7 | 2 | 6.0 |
| Mental Illness | None | 3 | 60.0 | 12 | 85.8 |
| | A Little | 1 | 20.0 | 1 | 7.1 |
| | A Lot | 1 | 20.0 | 1 | 7.1 |

with cognitive disabilities and mental illness. There was a consistent difference between youth and adult respondents on self-care: needs for assistance were less for adults than for youth in all disability categories.

**Communication**. Significant assistance with communication was required by a majority of youth and adults with sensory

disabilities. A significant minority of consumers with physical and cognitive disabilities also noted needs for substantial assistance. Youth and adults showed different levels of need for assistance. There were considerable decreases in stated need from youth to adulthood for persons with physical and sensory disabilities and mental illness.

**Table 8**

**Needs for Assistance with Communication for Youth and Adults by Disability Category**

| Disability Category | Response | Youth | | Adults | |
|---|---|---|---|---|---|
| | | Number | Percent | Number | Percent |
| Physical | None | 15 | 39.5 | 16 | 55.2 |
| | A Little | 7 | 18.4 | 4 | 13.8 |
| | A Lot | 16 | 42.1 | 9 | 31.0 |
| Cognitive | None | 11 | 17.2 | 20 | 32.3 |
| | A Little | 34 | 53.1 | 20 | 30.8 |
| | A Lot | 19 | 29.7 | 24 | 36.9 |
| Sensory | None | 5 | 29.4 | 13 | 39.4 |
| | A Little | 1 | 5.9 | 3 | 9.1 |
| | A Lot | 11 | 64.7 | 17 | 51.5 |
| Mental Illness | None | 2 | 40.0 | 8 | 57.1 |
| | A Little | 1 | 20.0 | 4 | 28.6 |
| | A Lot | 2 | 40.0 | 2 | 14.3 |

In contrast, persons with cognitive disabilities showed an increased need for assistance in communication in adulthood. This finding is probably due to the demand for sophisticated language in adulthood of importance to such adult roles as work, spouse, citizen, and homemaker.

**Learning**. Assistance in learning was a dominant need for consumers with three types of disabilities: cognitive, sensory, and mental illness. A significant minority of persons with physical disabilities noted a need for substantial assistance as well. As with communication, there

**Table 9**

**Needs for Assistance in Learning for Youth and Adults by Disability Category**

| Disability Category | Response | Youth | | Adults | |
|---|---|---|---|---|---|
| | | Number | Per-cent | Number | Per-cent |
| Physical | None | 4 | 10.5 | 14 | 48.3 |
| | A Little | 9 | 23.7 | 5 | 17.2 |
| | A Lot | 25 | 65.8 | 10 | 34.5 |
| Cognitive | None | 0 | 0.0 | 5 | 7.7 |
| | A Little | 5 | 7.8 | 11 | 16.9 |
| | A Lot | 59 | 92.2 | 49 | 75.4 |
| Sensory | None | 0 | 0.0 | 3 | 9.1 |
| | A Little | 1 | 5.9 | 4 | 12.1 |
| | A Lot | 16 | 94.1 | 26 | 78.8 |
| Mental Illness | None | 0 | 0.0 | 1 | 7.1 |
| | A Little | 0 | 0.0 | 1 | 7.1 |
| | A Lot | 5 | 100.0 | 12 | 85.8 |

were differences in level of need for assistance between youth and adult consumers. For all disability categories, fewer adult consumers indicated a substantial need for assistance than did youth consumers. The difference in need was particularly striking for persons with physical disabilities.

Getting from place to place. Personal mobility, the ability of a consumer to get from place to place, was a problem requiring substantial assistance for a majority of consumers with physical disabilities and for a significant minority of consumers with sensory disabilities. Little need for assistance was indicated for persons with cognitive disabilities or mental illness. There were also differences

**Table 10**

**Needs for Assistance with Getting from Place to Place for Youth and Adults by Disability Category**

| Disability Category | Response | Youth | | Adults | |
|---|---|---|---|---|---|
| | | Number | Per-cent | Number | Per-cent |
| Physical | None | 4 | 10.5 | 4 | 13.8 |
| | A Little | 9 | 13.2 | 5 | 17.2 |
| | A Lot | 29 | 76.3 | 20 | 69.0 |
| Cognitive | None | 51 | 79.7 | 50 | 76.9 |
| | A Little | 7 | 10.9 | 8 | 12.3 |
| | A Lot | 6 | 9.4 | 7 | 10.8 |
| Sensory | None | 10 | 58.8 | 13 | 39.4 |
| | A Little | 1 | 5.9 | 4 | 12.1 |
| | A Lot | 6 | 35.3 | 16 | 48.5 |
| Mental Illness | None | 5 | 100.0 | 13 | 92.9 |
| | A Little | 0 | 0.0 | 1 | 7.1 |
| | A Lot | 0 | 0.0 | 0 | 0.0 |

between youth and adults. A smaller proportion of adults with physical disabilities had substantial needs for assistance than did our youth with physical disabilities. In the case of sensory disabilities, the relationship was reversed: a

higher proportion of adults had substantial needs for assistance than did youth.

**Making decisions and managing life**. This lifeskill area is concerned with cognitive ability and sense of organization and is related to independence of functioning. Consumers with cognitive and sensory disabilities and mental illness all showed very high levels of need for assistance in youth.

**Table 11**

**Needs for Assistance in Making Decisions and Managing One's Life for Youth and Adults by Disability Category**

| Disability Category | Response | Youth | | Adults | |
|---|---|---|---|---|---|
| | | Number | Per-cent | Number | Per-cent |
| Physical | None | 4 | 10.5 | 13 | 44.8 |
| | A Little | 9 | 23.7 | 5 | 17.3 |
| | A Lot | 25 | 65.8 | 11 | 37.9 |
| Cognitive | None | 0 | 0.0 | 4 | 6.2 |
| | A Little | 6 | 9.4 | 4 | 6.2 |
| | A Lot | 58 | 90.6 | 57 | 87.6 |
| Sensory | None | 1 | 5.9 | 10 | 30.3 |
| | A Little | 10 | 58.8 | 10 | 30.3 |
| | A Lot | 6 | 35.3 | 13 | 39.4 |
| Mental Illness | None | 0 | 0.0 | 0 | 0.0 |
| | A Little | 0 | 0.0 | 1 | 7.1 |
| | A Lot | 5 | 100.0 | 13 | 92.9 |

Youth with physical disabilities also showed substantial need, but at a lower level than other groups. As with other functional limitations, there were differences between youth and adults in this functional area. Adults with physical,

cognitive and sensory disabilities showed considerable reduction in the proportion of persons having substantial need for assistance when compared to youth. While adults with mental illness also showed a reduction when compared with youth, the reduction was quite modest when compared with that of other disability categories. Over 90% of adults with mental illness needed substantial assistance in decisionmaking and life management suggesting an important target for future services and supports.

**Living independently**. As with the previous area of functional limitation, a majority of persons in all categories of disability showed substantial need for assistance in living

**Table 12**

**Needs for Assistance in Living on His or Her Own for Youth and Adults by Disability Category**

| Disability Category | Response | Youth | | Adults | |
|---|---|---|---|---|---|
| | | Number | Per-cent | Number | Per-cent |
| Physical | None | 0 | 0.0 | 2 | 6.9 |
| | A Little | 10 | 29.4 | 2 | 6.9 |
| | A Lot | 24 | 70.6 | 25 | 86.2 |
| Cognitive | None | 3 | 5.0 | 0 | 0.0 |
| | A Little | 19 | 31.7 | 2 | 3.1 |
| | A Lot | 38 | 63.3 | 63 | 96.9 |
| Sensory | None | 3 | 18.8 | 4 | 12.1 |
| | A Little | 4 | 25.0 | 9 | 27.3 |
| | A Lot | 9 | 56.2 | 20 | 60.6 |
| Mental Illness | None | 0 | 0.0 | 0 | 0.0 |
| | A Little | 1 | 20.0 | 2 | 14.3 |
| | A Lot | 4 | 80.0 | 12 | 85.7 |

independently. This is not intended as an ironic statement. Data suggest, rather, that groundwork must be laid and, for many, certain supports put in place, for a consumer to establish and stabilize an independent lifestyle. Differences between youth and adults were clear and consistent. While the proportion of youth needing substantial assistance was rather high, the proportion needing substantial assistance was even higher for all categories of disability in adulthood. The increases were greatest for persons with physical and cognitive disabilities and appear to reflect a view among a large majority of all persons with disabilities that independent adulthood for most consumers is not possible without a substantial level of assistance.

**Maintaining a source of income**. As with the previous two areas of limitation, maintaining an income is related to independent functioning in the adult world. Like each of the previous two areas of limitation, both youth and adults of each disability category indicated a substantial need for assistance in this area. As with living independently, adults of each disability category showed a higher proportion needing substantial assistance than did youth. These, and other findings to be reported later, suggest that maintenance of income is an important factor to the adult consumer in the perception of his or her independence.

**Disabilities and functional limitations**. Using the findings given above, it is possible to profile each category

**Table 13**

**Needs for Assistance in Maintaining a Source of Income for Supporting Self for Youth and Adults by Disability Category**

| Disability Category | Response | Youth | | Adults | |
|---|---|---|---|---|---|
| | | Number | Per-cent | Number | Per-cent |
| Physical | None | 1 | 2.9 | 4 | 13.8 |
| | A Little | 6 | 17.7 | 1 | 3.4 |
| | A Lot | 27 | 79.4 | 24 | 82.8 |
| Cognitive | None | 2 | 3.3 | 3 | 4.6 |
| | A Little | 21 | 35.0 | 3 | 4.6 |
| | A Lot | 37 | 61.7 | 59 | 90.8 |
| Sensory | None | 2 | 12.5 | 5 | 15.2 |
| | A Little | 5 | 31.3 | 8 | 24.2 |
| | A Lot | 9 | 56.2 | 20 | 60.6 |
| Mental Illness | None | 0 | 0.0 | 0 | 0.0 |
| | A Little | 1 | 20.0 | 0 | 0.0 |
| | A Lot | 4 | 80.0 | 14 | 100.0 |

of disability by describing its most common and prominent functional limitations. The profiles presented below are based on the following criterion: one-half or more of consumers in a disability category indicated "A Lot" of (i.e., substantial) need for assistance. Profiles for each disability category are presented for youth (Figure 5) and for adults (Figure 6).

Youth with physical disabilities have a number of prominent functional limitations, including self-care, learning, getting from place to place, making decisions and managing life, living independently, and maintaining a source of income. In adulthood, the list is reduced somewhat. Yet

data indicate that three areas of substantial need remain for over half of adults with physical disabilities: getting from place to place, living independently, and maintaining a source of income.

**Figure 5**

**Significant Needs* for Assistance by Disability Category for Youth**

| Life Task | Disability Category | | | |
|---|---|---|---|---|
| | Physical | Cognitive | Sensory | Mental Illness |
| Self-Care | x | | | |
| Communication | | | x | |
| Learning | x | x | x | x |
| Getting From Place to Place | x | | | |
| Making Decisions/ Managing Life | x | x | x | x |
| Living on Own | x | x | x | x |
| Maintaining Source of Income | x | x | x | x |

* one half or more indicating "A Lot" of need for assistance.

**Figure 6**

**Significant Needs* for Assistance by Disability Category for Adults**

| Life Task | Disability Category | | | |
|---|---|---|---|---|
| | Physical | Cognitive | Sensory | Mental Illness |
| Self-Care | | | | |
| Communication | | | x | |
| Learning | | x | x | x |
| Getting From Place to Place | x | | | |
| Making Decisions/ Managing Life | | | | x |
| Living on Own | x | x | x | x |
| Maintaining Source of Income | x | x | x | x |

* one half or more indicating "A Lot" of need for assistance.

A large proportion of youth with cognitive disabilities show substantial needs for assistance in the following areas: learning, making decisions and managing life, living independently, and maintaining a source of income. Needs related to functional limitations in adults are only slightly different. In adulthood, over half of consumers with cognitive disabilities retain substantial needs for assistance in learning, living independently, and maintaining a source of income.

Youth with mental illness showed the same patterns of need as did persons with cognitive disabilities. That is, substantial assistance by over half of youth with mental illness was indicated for the following life tasks: learning, making decisions and managing life, living independently, and maintaining an income. Unlike persons with cognitive disabilities, however, the same pattern holds in adulthood. Adults with mental illness have substantial needs for assistance in the same life skill areas as do youth with mental illness.

Over half of persons with sensory disabilities show substantial needs for assistance in the following life skill areas: communication, learning, making decisions and managing life, living independently, and maintaining a source of income. For adults, this list of skill areas requiring substantial assistance is reduced only slightly. Most adults with sensory disabilities still required substantial assistance in communication, learning, living independently, and in maintaining a source of income.

## Life Roles in Youth and Adulthood

From the perspective of life roles, the times of childhood and adolescence are considerably less complex then is the time of adulthood. Only three roles dominate childhood, those of child, student and leisure person. That is not to say that childhood is unimportant. On the contrary,

it is a time of developing physical, emotional, and social skills and the anchoring of one's personality. This period lays a foundation that predisposes the child to certain ways of being, believing, and behaving in later life.

In adolescence an additional role is tried on. Most teens initiate their work life at this time in preparation for a career. Dating behavior, also initiated at this time, prepares the teen for the roles of spouse and parent. Late adolescence is a time when traditional citizenship activities (e.g., voting) may be initiated.

Adulthood is characterized by greater diversity of life roles than any other period of life. To the youth roles of child, student, leisure person, worker, and citizen are added the adult roles of spouse, homemaker, parent, and pensioner. These nine life roles largely define how we choose or are allowed to be engaged with the world.

One other issue is essential to the understanding of the relationships among the various life roles: successful engagement in early roles pave the way for successful engagement in later roles. The child, for example, who learns successful competition and cooperation skills at school and in leisure activities is better prepared for the requirements of work. The child, adolescent and adult who learn successful leisure or citizenship skills are best prepared for the role of pensioner.

Below we have developed information on life roles at different age levels. In reading these brief profiles, we suggest that you think developmentally. That is, we encourage you to consider what the absence of access to a major life role in one part of life would mean for consumers in later life stages. Below we have profiled the nine life roles, in the approximate order of taking on the role.

Child. Only limited information on the role of the child can be gleaned from this survey. This limited picture, based on "the average child", is of a child living in a single-family home with one or more siblings who do not have a disability. The child commonly experiences fairly strong feelings of loneliness and remoteness from others. The incidence of these feelings increases through adolescence. No information was available on the nature of family relationships or on the quality of participation in the family homelife of a youth with a disability. A slightly more detailed summary on the role of the child is contained in Chapter 5, Integration, under the heading "Roles of child, parent, and spouse."

Student. As reviewed in the chapters on independence, integration, and productivity, the survey offered limited insight in the specific nature of the student role. There is information, however, on educational setting, and on satisfaction with educational services and supports that are used to define the role of student for persons with

disabilities. Of students between the ages of 0 and 5 currently receiving educational services, about three-quarters are either in a special class in a regular school (48.7%) or a special day school (25.6%). There is a shift in setting in the elementary years with almost two-thirds of children aged six to thirteen enrolled in special classes in regular schools (63.8%). Only about fifteen percent are placed in regular classes of regular schools (10.3%) or resource rooms in regular schools (5.2%). At the high school level (i.e., ages 14-22), there is again a shift in the educational settings where students spend most of their time. Almost a third (32.1%) remain in special classes in regular schools, with about a quarter each in special day schools (25.0%) and regular classes in regular schools (23.2%). In adulthood (i.e., after age 22), most consumers, no longer having the mandated special services of local school systems available to them, are either enrolled in regular classes in regular schools (39.5%) or special day schools (19.1%). The changing nature of these settings across traditional school structures (i.e, pre-school; elementary; high school; adult) suggest the likelihood of discontinuity in educational resources, quality of instruction, and the opportunity for peer relationships likely to have a profound impact on the meaningfulness and richness of the student role across the lifespan. Further research needs to be conducted on the effects of discontinuity

of educational settings on the lifestyles of persons with developmental disabilities.

Additional information on the role of student is available from data on satisfaction and needs related to educational setting for the age spans introduced above.

Interestingly, satisfaction with school is greatest on either end of the age continuum. The parents of children aged 0 to 5 years indicated that about nine of ten (91.2%) were satisfied with their child's educational experience, about the same as the percentage of adults indicating satisfaction with their educational experiences (90.0%). Between those ages, satisfaction drops to 81.7% in the elementary years and 65.1% in adolescence. A review of satisfaction with and needs for services can help to explain these drops in satisfaction.

The elementary school years are the time when the foundation for learning is initiated. This learning includes not only cognitive skills but also physical and social ones as well. Additionally, it is a time when many children deal with the basic concepts of "different" versus "same" with regard to peers and friendship. It is a period when "same" and "belonging" appear synonymous. Yet this is a period with the highest incidence of isolating children with disabilities from their peers without disabilities by placing them in special classrooms. We have noted that many children of this age feel lonely and isolated. Is it possible that, for many children with disabilities, one of their earliest learnings

from school is that they are different and need to be kept apart from peers who are not so special? Academically, it is a time when the foundations of learning are laid. It is a maxim in public schools that those who fall behind in basic skills remain behind, failures in their educational roles. About one in every five (19.0%) consumers taking this survey expressed a need for basic literacy training. Parents of elementary school children and the children themselves expressed a strong need for special assistance during these years. The preferred methods of that assistance were the provision of services consistent with any educational setting, not just ones specially designed for consumers. These included services such as after-school tutors and personal care attendants. Table 14 shows expressed needs for those services across the lifespan. These data show significant needs for special personal assistance in pre-school and elementary grades that greatly decreases during adolescence and adulthood.

Adolescence is a time of considerable change for youth, intellectually, socially, and physically. From the perspective of student roles, two goals are dominant. First, there is a further articulation of basic literacy skills and a broadening of general knowledge. Second, there is an exploration of the world of work that is followed by a

**Table 14**

**Number and Percentage of Consumers Expressing Needs for After-School Tutors and Personal Care Attendants: By Age Groups**

| | AGE | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | 0-5 | | 6-13 | | 14-22 | | 23 and over | |
| | Number | Percent | Number | Percent | Number | Percent | Number | Percent |
| A. Personal Care Attendant | | | | | | | | |
| Strong, Urgent or Primary Need | 10 | 37.0 | 16 | 41.0 | 6 | 17.6 | 11 | 15.5 |
| Not Needed at all | 12 | 44.4 | 17 | 43.4 | 28 | 82.4 | 53 | 74.7 |
| B. After-School Tutor | | | | | | | | |
| Strong, Urgent or Primary Need | 8 | 28.6 | 15 | 34.1 | 2 | 5.9 | 4 | 6.1 |
| Not Needed at all | 15 | 53.6 | 20 | 45.5 | 28 | 82.4 | 60 | 90.9 |

narrowing of career-related choices. For late adolescence is a time of exploration of potential careers in preparation for the work roles of adulthood.

The current survey requested information on three types of student roles related to career exploration and general preparation for adult roles. Data on adult literacy suggest that a little over a tenth of adolescent (11.8%) and adult (15.3%) consumers have strong, urgent or primary needs for additional education in this area. By far the greatest needs for services related to the adolescent student role is for technical and vocational education. About two-thirds (66.0%) of adolescent consumers expressed a strong, urgent, or primary

need for these services. Forty percent of adult consumers expressed a need for those same services. Among adolescents and adults not currently receiving services but with needs for technical or vocational education, the most common reason given for not receiving services was "not appropriate to needs or person doesn't like the service." For adults, additional reasons for not receiving services included "not eligible by type or degree of disability," "too expensive," and "service not available." Despite the very high level of need indicated for these services among adolescents, a high proportion of adolescents indicated dissatisfaction with technical and vocational education services they had received (38.9%). The dominant reason given for dissatisfaction was "not suited to individual needs." These data on technical and vocational education are presented in Table 15.

A second type of educational service often related to vocational exploration is post-secondary education or college. Data on needs for post-secondary education for adolescents and adults indicate that almost one in every six consumers had a strong, urgent, or primary need for these services. Those not receiving these services gave as their dominant reasons "too expensive" and "not eligible by type and degree of disability." In contrast to technical and vocational education, post-secondary education received generally favorable ratings from consumers receiving services at the time of the survey. These data are presented in Table 16.

**Table 15**

**Number and Percentage of Consumers Satisfied with and Needing Technical and Vocational Education Services: Adolescent and Adult Consumers**

| | Adolescent | | Adult | |
|---|---|---|---|---|
| | Number | Percent | Number | Percent |
| A. Need | | | | |
| Strong, Urgent or Primary Need | 33 | 66.0 | 36 | 40.0 |
| Not Needed | 13 | 26.0 | 37 | 41.1 |
| B. Satisfaction | | | | |
| Very Satisfied or Satisfied | 10 | 55.6 | 25 | 89.3 |
| Dissatisfied or Very Dissatisfied | 7 | 38.9 | 2 | 7.1 |

In summary, information on student roles is complex and appears to be best analyzed by major educational period: preschool, elementary, high school and adult. Of the four periods, consumer satisfaction is lowest in the elementary and high school years.

In the elementary years, the role of student aims to develop basic physical, social and intellectual skills. Survey results indicate that a primary barrier in accomplishment of those aims for consumers is the absence of appropriate educational supports (e.g., attendants; after-school tutors). In the high school years, the role of student

**Table 16**

**Number and Percentage of Consumers Satisfied with and Needing Post-Secondary Education Services: Adolescent and Adult Consumers**

| | Adolescent | | Adult | |
|---|---|---|---|---|
| | Number | Per-cent | Number | Per-cent |
| A. Need | | | | |
| Strong, Urgent or Primary Need | 6 | 17.6 | 12 | 16.7 |
| Not Needed | 13 | 67.7 | 47 | 65.3 |
| B. Satisfaction | | | | |
| Very Satisfied or Satisfied | 2 | 100.0 | 9 | 69.2 |
| Dissatisfied or Very Dissatisfied | 0 | 0.0 | 3 | 23.1 |

aims to further articulate basic skills, to broaden general knowledge, and to explore and prepare for a career. Several barriers appear to exist for consumers attempting to satisfy this aim. Small but significant proportions of adolescent consumers indicate needs for adult literacy and post-secondary education. A majority of adolescent respondents indicated a need for technical or vocational education. Unfortunately, a rather large proportion of adolescent consumers currently enrolled in such programs find them unsatisfactory, mostly due to their inability to meet individual needs. Additional research on adolescent consumer needs for technical and

vocational education and on alternative service system designs in Virginia that do and do not show consumer satisfaction with these services is needed.

**Leisure person**. The role of leisure person is often defined by what a person chooses to do in the time left over after engaging in other "mainstream" roles. We will review information later in this report that suggests that most consumers have limited access to a number of mainstream roles, particularly those of adulthood (e.g., worker; parent). It follows that there should be additional time for leisure pursuits for many persons with severe disabilities. We hypothesized that adult consumers would show a higher level of involvement in leisure activities than would youthful consumers.

Our data indicate otherwise, however. Table 17 compares the percentage of consumers of different ages given some degree of choice in selecting evening and weekend activities to that of consumers given no choice in such activities. It is clear from this table that choice rises steadily through adolescence but shows a moderate decline between adolescence and adulthood. It is not clear why this drop in the incidence of independent decisionmaking occurs but it is consistent with other data. The frequency of visits to friends and relatives and restaurants both show similar decreases in adulthood

**Table 17**

**Number and Percentage of Consumers Given Some Level of Choice Versus No Choice in Selecting Evening and Weekend Activities: Groups at Pre-School, Elementary, High School, and Adult Ages.**

| Do you choose what you do weekends and evenings? | AGE | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | 0-5 | | 6-13 | | 14-22 | | 23 and over | |
| | Number | Percent | Number | Percent | Number | Percent | Number | Percent |
| "Yes, without Assistance" or "Yes, with Assistance" | 16 | 41.0 | 42 | 70.0 | 50 | 89.2 | 129 | 83.8 |
| "No" | 14 | 35.9 | 12 | 20.0 | 6 | 10.7 | 20 | 13.0 |

(Table 18). Furthermore, similar patterns show up in data on involvement in traditional leisure activities. Attendance at all passive leisure activities surveyed (e.g., movies, live theater, live music, sporting events) showed a drop in

**Table 18**

**Number and Percentage of Consumers Visiting Friends and Relatives and Visiting Restaurants in Past Year: Groups by Age**

| | AGE | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | 0-5 | | 6-13 | | 14-22 | | 23 and over | |
| | Number | Percent | Number | Percent | Number | Percent | Number | Percent |
| A. Visits to Friends & Relatives | | | | | | | | |
| Once a Month or More | 37 | 94.8 | 57 | 95.0 | 51 | 91.9 | 132 | 87.4 |
| Never | 2 | 5.1 | 1 | 1.7 | 1 | 1.8 | 8 | 5.3 |
| B. Restaurants | | | | | | | | |
| Once a Month or More | 28 | 71.8 | 49 | 83.1 | 45 | 81.8 | 119 | 78.8 |
| Never | 4 | 10.3 | 4 | 6.8 | 2 | 3.6 | 14 | 9.3 |

frequency between either elementary or high school ages and adulthood. In active leisure pursuits, there was a large drop in frequency of attendance at recreational facilities. The only increase in leisure activities in adulthood was for attendance at meetings of community and civic groups. These data are presented in Table 19.

There are also data on the nature of social contacts across the age span. Generally, the patterns seen for leisure activities also prevail for social contacts. For example, while 53.4% of children aged 6 to 13 and 53.6% of adolescents know four or more of the ten families living closest to them by name, only 35.1% of adults can make that claim. A similar relationship holds for the number of families the consumer has visited with or been visited by. Furthermore, adults show the lowest percentage of any group indicating that they have friends without disabilities that they see regularly. Adults also have the highest percentage of any group indicating that most of their friends have disabilities. Data on social relationships and age are presented in Tables 20 and 21.

Data will be introduced in the following chapters to suggest that several adult life roles are limited in their potential for participation by most consumers when compared to those of persons without disabilities. Such life roles include worker, parent, spouse, and pensioner. Often, a limitation in one life role can mean additional time for other

## Table 19

## Number and Percentage of Consumers Attending Various Passive and Active Leisure Activities: By Age Group

| | AGE | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | 0-5 | | 6-13 | | 14-22 | | 23 and over | |
| | Number | Percent | Number | Percent | Number | Percent | Number | Percent |
| A. Passive Activities | | | | | | | | |
| - Movies | | | | | | | | |
| Once or More Quarterly | 2 | 5.3 | 16 | 26.7 | 30 | 55.5 | 55 | 36.7 |
| Not in Past Year | 24 | 63.2 | 17 | 28.3 | 11 | 20.4 | 59 | 39.3 |
| - Live Theater | | | | | | | | |
| Once or More Quarterly | 1 | 2.6 | 5 | 8.5 | 7 | 13.0 | 18 | 12.0 |
| Not in Past Year | 27 | 71.0 | 25 | 42.4 | 28 | 51.9 | 88 | 58.7 |
| - Live Music Events | | | | | | | | |
| Once or More Quarterly | 1 | 2.6 | 4 | 6.8 | 12 | 22.2 | 13 | 8.7 |
| Not in Past Year | 30 | 79.0 | 32 | 54.2 | 23 | 42.6 | 89 | 59.3 |
| - Sporting Events | | | | | | | | |
| Once or More Quarterly | 11 | 28.9 | 23 | 38.3 | 14 | 25.9 | 40 | 26.8 |
| Not in Past Year | 21 | 55.3 | 23 | 38.3 | 22 | 40.7 | 76 | 51.0 |
| B. Active Activities | | | | | | | | |
| - Recreation (e.g., YMCA) | | | | | | | | |
| Once or More Quarterly | 7 | 18.4 | 30 | 50.8 | 13 | 24.1 | 13 | 8.8 |
| Not in Past Year | 29 | 76.3 | 27 | 45.8 | 33 | 61.1 | 118 | 79.7 |
| - Community & Civic Groups | | | | | | | | |
| Once or More Quarterly | 7 | 18.9 | 15 | 25.0 | 9 | 17.0 | 39 | 26.5 |
| Not in Past Year | 26 | 70.3 | 33 | 55.0 | 37 | 69.8 | 94 | 64.0 |

## Table 20

**Number and Percentage of Consumers Knowing the Names of and Visiting with the Ten Families Living Closest to Them: By Age Group**

| | AGE | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | 0-5 | | 6-13 | | 14-22 | | 23 and over | |
| | Number | Percent | Number | Percent | Number | Percent | Number | Percent |
| Able to Name More than 4 of 10 Closest Neighborhood Families | 14 | 36.8 | 31 | 53.4 | 30 | 53.6 | 52 | 35.1 |
| Has Visited with or Been Visited By 4 of 10 Closest Neighborhood Families | 13 | 33.3 | 29 | 49.2 | 22 | 39.3 | 34 | 23.1 |

## Table 21

**Number and Percentage of Consumers Having Non-Disabled Friends They Frequently Visit and With A Majority of Friends Having Disabilities: By Age Group**

| | AGE | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | 0-5 | | 6-13 | | 14-22 | | 23 and over | |
| | Number | Percent | Number | Percent | Number | Percent | Number | Percent |
| Have Non-Disabled Friends that are Regularly Seen | 32 | 82.1 | 48 | 80.0 | 41 | 73.2 | 111 | 72.6 |
| Majority of Friends have Disabilities | 11 | 29.0 | 24 | 40.0 | 25 | 45.5 | 77 | 50.7 |

life roles. Long-term trends in the United States suggest that time released from traditional roles such as work are often placed in leisure activities. Results of this survey strongly suggest that that is not the case for adult

consumers, however. Adult consumers show a reduction in all types of leisure pursuits when compared to their earlier years--in informal leisure activities (e.g., going to restaurants); in passive leisure participation (e.g., going to movies); in active leisure participation (e.g., recreation); in social participation (e.g., visiting neighbors). Precisely how consumers choose to spend their time is not clear from the survey. What is clear is that it is not spent in traditional leisure activities associated with community and neighborhood participation. Understanding of time use by consumers is an area for research little explored at this time. It is worthy subject for further evaluation.

**Worker**. The role of worker is defined in this section as a consumer who engages in paid employment. Of our sample of adults, a slight majority (52.4%) were available for work. Of consumers available for work, 61.8% were working full-time and 23.7% were working part-time. Full-time employees worked an average of 37 hours weekly and had a projected annual income of $12,214. Part-time employees worked considerably fewer hours and had considerably lower projected annual earnings.

Limited data from the survey suggest that most consumers work at relatively low-status, dead-end jobs. Almost two-thirds of consumers who worked were working in the two lowest categories of occupation: operatives and laborers or service, craft, agricultural, forestry, and fishing workers. This fact

alone accounts for most of the very low projected earnings for full and part-time employed consumers. Yet about one-fifth of consumers (20.7%) worked in professional positions such as teacher, librarian or manager.

Due to design of the survey, no information on the quality of worklife for consumers with disabilities was gathered. Such information on the worklife of consumers in Virginia must await additional research.

Citizen. The concept of citizen involves the joining with others and use of energy for the betterment of a group of people. That group could be one of a special interest, neighbors, community or nation. While the citizen role was not a major thrust of the survey, several items offer a window into the citizen roles of Virginia's consumers.

First of all, we may say that Virginia's consumers tend to stress independence rather than interdependence in their citizen roles. About four of every ten (39.3%) adult consumers voted in the last general election and about 53.3% provide weekly assistance to family, friends or neighbors. These are activities carried out by individual consumers that define an individual citizen's role. In contrast, only 27.0% were members of advocacy or consumer groups and only 36.0% attended the meetings of community or civic organizations. These organizations require the interdependency of citizens to accomplish their aims. These findings suggest a tendency on the part of Virginia's consumers to be active as citizens

in ways that limit the influence of the consumer advocacy movement in Virginia. The reasons for such preferences for involvement are not clear. Again, there is a need for research to clarify reasons for Virginia's consumers to behave independently from one another in efforts that would greatly benefit from mutual support.

**Spouse**. No items on the survey requested information on the role of spouse. It should be noted, however, that this mainstream role is a somewhat unusual one for consumers: 81.2% of adults consumers over the age of 20 had never married and, of those who had, 41.4% had had marriages that were terminated by divorce.

**Homemaker**. Relatively few of the survey items addressed the life role of homemaker. About a fifth (21.9%) of adult consumers reported doing no housework in the week preceding the survey. The remaining 78.1% reported doing housework from between one and forty hours with an average time of 4.4 hours. A large percentage of consumers indicated a need for homemaking assistance or training (Due to survey design, it was not possible to differentiate consumers needing assistance from those needing training).

**Parent**. No items of the survey requested information on the life role of parent.

**Pensioner**. The survey failed to address the life role of pensioner for persons with developmental disabilities.

**Summary on Life Roles**

Life roles are important to our lives because they structure how we spend our time, what we're involved in doing, and who we get to know. It is safe to say that none of us would be who and what we are if it were not for the structure of our life roles.

But life roles are not equally accessible to everyone. Like a child in a wheelchair before the steps of a public library, so many persons with disabilities stare at inaccessible roles most Virginians take for granted.

One reason for the inacccessibility of life roles to many persons with developmental disabilities has to do with the functional limitations of particular disabilities. Deafness, for example, often causes difficulty in communicating that may limit choices in certain roles. Yet it is important to stress that in most cases, functional limitation does not prohibit a role--instead, it dictates that a person with a disability be more select in choosing among options for that role.

Survey data strongly suggest that two types of functional limitation are common to most developmental disabilities: living independently and maintaining a source of income. Each of these functional limitations have a profound impact on the life roles of persons with developmental disabilities. Other functional limitations in adults tend to be common to persons with some types of disability but not others. These include

learning (i.e., for cognitive and sensory disabilities and mental illness), communication (e.g., for sensory disabilities), making decisions and managing life (e.g., for mental illness), and getting from place to place (e.g., for physical disabilities). These too have a profound effect on the life roles of persons with developmental disabilities but the effects are different for different disability categories. Figure 7 presents the unique cluster of functional limitations most common to each disability group along with the life roles thought to be impacted most by each.

Specific information on life roles was rather variable on the survey. Virtually no information was available on some roles (i.e., child; parent; spouse; pensioner). For some others (i.e., citizen; homemaker), modest information was available. As citizens, adult consumers were found to prefer informal (e.g., helping a friend) to formal (e.g., joining a club or group) activities, and to have relatively low involvement in the traditional structures and mechanisms of political influence. As homemakers, most consumers were found to spend a modest amount of time in homemaking activities. Many emphasized a need for assistance or training in this area.

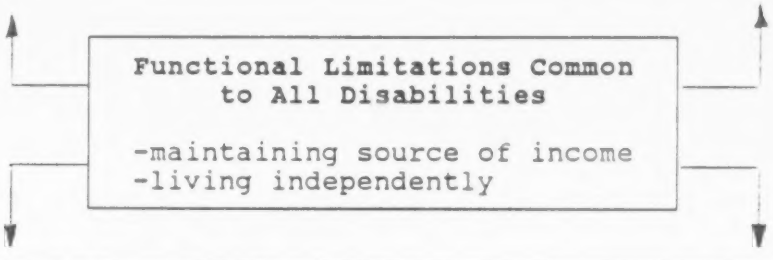
Primary emphasis of the survey was on three life roles: student, leisure person, and worker. For the student role, survey results suggested important differences across the age span. In the elementary years, key policy issues were related

to provision of special education services on the one hand, and degree of classroom integration on the other. Currently, provision of special education services in segregated classrooms predominates. Our data do suggest the importance of special educational services. They also suggest that provision of services in integrated classrooms significantly contributes to life satisfaction. Consumers noted high levels of need for the educational services that would contribute to success in integrated classrooms--after-school tutors and classroom attendents. These results suggest an education philosophy and strategy that is radically different from that currently in place with most of Virginia's school systems. In the adolescent years, concerns over career predominate. Three educational foci are paramount. First, data on needs suggest the importance of attainment of basic literacy for all persons with developmental disabilities. Second, there is a need for acceptable technical and vocational education. Currently, satisfaction with these services is rather low, largely due to a lack of individuation of services. Last, for a small but significant proportion of consumers, there is an important need for post-secondary education. Given findings related to the low income for persons with developmental disabilities (see Chapter 7, Productivity), problems with college education are not surprising--most consumers are simply too poor to pay for them.

**FIGURE 7**

**Functional Limitations Common to All Disability Categories and Functional Limitations and Hypothesized Life Roles Impacted for Specific Disability Categories**

| Physical Disabilities | Cognitive Disabilities |
|---|---|
| A. Functional Limitation<br>-getting from place to place<br><br>B. Impacted Life Roles<br>-child<br>-leisure person<br>-worker<br>-spouse<br>-homemaker | A. Functional Limitation<br>- learning<br><br>B. Impacted Life Roles<br>-student<br>-worker<br>-citizen<br>-spouse<br>-parent |




| Mental Illness | Sensory Disabilities |
|---|---|
| A. Functional Limitation<br>-learning<br>-making decisions and managing life<br><br>B. Impacted Life Roles<br>-student<br>-worker<br>-citizen<br>-spouse<br>-homemaker<br>-parent | A. Functional Limitation<br>-learning<br>-communication<br><br>B. Impacted Life Roles<br>-child<br>-student<br>-leisure person<br>-worker<br>-spouse<br>-parent |

This survey provided considerable data on leisure activities. Virtually all of them led to the same conclusion--that adult consumers show decreases in virtually all types of leisure activities when compared with youth. Yet traditional adult roles (i.e., worker; spouse; parent), that consume most adult time are denied to a large proportion of persons with developmental disabilities. One question remains: How do adult consumers spend their time?

A review of data on work available to persons with developmental disabilities is not comforting. It is obvious from our data that some progress has been made. Yet compared to most subgroups of Americans, the proportion of persons with developmental disabilities who are working is quite low. Average projected annual income for working consumers is just over $12,000. A majority of working consumers were found to work in low-status, dead-end jobs.

## CHAPTER 4

## Life Supports and Services

Consumer satisfaction and needs in eight categories of life supports and services are presented in this chapter. These categories are (a) case coordination services, (b) residential services, (c) educational services, (d) vocational and adult day services, (e) health services, (f) transportation services, (g) other individual support services, and (h) caregiver support services. For each category, results are given first on satisfaction with the services by those currently receiving the service. This is followed by information on the degree of need for the service indicated by persons completing the survey. There is also a brief section presenting the level of satisfaction with Virginia's service agencies as indicated by members of our sample.

While some information was provided in previous chapters for each of four disability categories (i.e., cognitive, physical, sensory, emotional), it was not possible to do so here because of the limited number of persons receiving services in each category. Only accumulated data is presented across disability categories. Results presented below also represent data for both children and adults. Policymakers and other persons interested in a more detailed analysis and understanding of data as they apply to specific populations

are requested to contact the authors listed at the beginning of this report.

## Case Coordination Services

These services include individualized needs assessment, planning, coordination, and follow-up services necessary to make the delivery system work well for individuals with disabilities. Level of consumer satisfaction is requested on three common services in this area: assessment and plan development, case management, and information and referral. Table 22 gives the results.

**Table 22**

**Satisfaction with Case Coordination Services**

| Service | Number of Persons Responding | Percent Very Satisfied or Satisfied | Percent Dissatisfied or Very Dissatisfied |
|---|---|---|---|
| Assessment/Plan Development | 151 | 75.5 | 13.2 |
| Case Management | 135 | 71.1 | 12.6 |
| Information and Referral | 112 | 77.7 | 10.7 |

About half of our sample currently receives some kind of case coordination service. Satisfaction with these services is generally high with about three out of every four persons indicating that they are very satisfied or satisfied. Just over one of every ten persons receiving these services responded that they were dissatisfied or very dissatisfied. Primary reasons for dissatisfaction included comments that some services failed to be appropriately individualized and

that, in some cases, persons were unable to receive enough of the service to truly help them.

Relative to needs, the only question asked that was related to Case Coordination Services was a question about needs for case management services. Results are presented in Table 23. Results show an approximate even split with about

**Table 23**

**Need for Case Management Services**

| Level of Need Indicated | Number of Responses | Percent Responding at Each Level of Need |
|---|---|---|
| Not Needed at All | 60 | 31.5 |
| Slight or Moderate Need | 57 | 29.8 |
| Strong, Urgent or Primary Need | 74 | 38.7 |
| TOTAL | 191 | 100.0 |

a third of respondents indicating no need for services, a third indicating a slight or moderate need, and a third indicating strong, urgent or primary need. Reasons given for not currently receiving case management services included statements that the services were not appropriate to the needs

of the person with a disability, lack of knowledge that the service existed*, and "other reasons."

## Residential Services

These services focus on living arrangements and the supports necessary to maintain living quarters and may include supervision needed to ensure safety and well-being and limited training in self-care and community living. Supports may be external rather than at the place a person resides. Satisfaction with different residential services by persons currently receiving those services is presented in Table 24. This table demonstrates some significant differences in

**Table 24**

**Satisfaction with Residential Services**

| Residential Service | Number of Persons Responding | Percent of Persons Satisfied or Very Satisfied | Percent of Persons Dissatisfied or Very Dissatisfied |
|---|---|---|---|
| Group Home or Apartment | 27 | 96.3 | 3.7 |
| Supervised Home or Apartment | 7 | 85.7 | 14.3 |
| Family Care | 24 | 79.2 | 16.7 |
| Institution | 29 | 75.9 | 17.2 |
| Room and Board Domiciliary | 15 | 73.3 | 16.6 |
| Nursing Home | 3 | 33.3 | 66.6 |
| TOTAL RECEIVING RESIDENTIAL SERVICES | 105 | | |

*There is an indication that lack of awareness of available case management services may be especially true for persons with physical disabilities.

Supervised homes and apartments also received a relatively high rating for satisfaction. These residential settings are those generally considered to allow the greatest independence for residents.

Following these two services is a grouping of three residential options, all with satisfaction rates of around 75% and dissatisfaction rates between 15-20%. Finally, nursing homes received the lowest satisfaction rates though this finding should be interpreted with caution since it is based on the responses of only three persons.

It is instructive to compare level of satisfaction with large residential facilities with that of small residential facilities. This relationship is presented in Table 25. For each type of residential facility, consumers indicate greater satisfaction with facilities with fewer residents that with those with a greater number of residents. For example, consumers were more satisfied with small nursing homes than large ones.

Summarizing data on residential facilities, we may say that consumers appear to be most satisfied with residential facilities offering both personal independence and a relatively small number of fellow residents.

A relatively small percentage of our sample were receiving homemaker assistance or training (5.13%). Of those, 85.0% were satisfied or very satisfied while 10.0% indicated

## Table 25

## Satisfaction with Residential Services: Small Versus Large Residential Facilities

| Residential Service | Small Facility | | Large Facility | |
|---|---|---|---|---|
| | Number of Respondents | Percent Satisfied or Very Satisfied | Number of Respondents | Percent Satisfied or Very Satisfied |
| Group Home or Apartment | | | | |
| More than 10 | | | 14 | 92.9 |
| Fewer than 10 | 13 | 100.0 | | |
| Institutions | | | | |
| More than 50 | | | 20 | 75.0 |
| Fewer than 50 | 9 | 77.7 | | |
| Nursing Home | | | | |
| More than 50 | | | 0 | 0.0 |
| Fewer than 50 | 1 | 100.0 | | |
| TOTAL | 23 | 91.3 | 34 | 77.7 |

that they were very dissatisfied with the service. About two-fifths (40.1%) of respondents did indicate either a slight or moderate need (14.1%) or strong, urgent or primary need (26.0%) for these services. The most common reasons for not receiving the homemaker assistance or training services were that the services were not available, not appropriate to the consumer's needs or "other reason."

Relatively few consumers (6.2%) were receiving housing subsidies (e.g., Section 8) at the time of the survey. Of the eighteen receiving subsidies, 16 (88.9%) indicated that they were satisfied or very satisfied with these services. Only 1 (5.6%) indicated dissatisfaction with housing subsidies. When consumers were asked about level of need for

housing subsidies, 11.8% indicated a slight or moderate need and 22.4% indicated a strong, urgent or primary need. The most common reasons for not receiving these services were "not eligible because of income or means" and "other reasons."

Consumers were also asked about satisfaction with and need for architectural modification of their residences. Of the fifteen consumers who had received these services, 10 (66.7%) indicated that they were satisfied or very satisfied while 3 (20.0%) responded that they were dissatisfied or very dissatisfied. The primary reason for dissatisfaction was "too expensive." Better than one in ten consumers (12.6%) indicated a slight or moderate need for these services and 14.4% of consumers indicated a strong, urgent or primary need. Primary reasons for not receiving these services included "too expensive," "service that is available is not appropriate to needs or person doesn't like the service," and "any other reason."

## Educational Services

Educational services include all those designed to enhance the physical, communication, social, affective, and cognitive development of persons aimed at development of skills and behavior needed to maintain a lifestyle as similar to that of persons without disabilities as possible.

Results generally indicated that satisfaction with educational services is high. Table 26 gives the percentage

skills and behavior needed to maintain a lifestyle as similar to that of persons without disabilities as possible.

Results generally indicated that satisfaction with educational services is high. Table 26 gives the percentage of persons satisfied and dissatisfied for each educational service. Per cent of persons indicating "satisfied" or "very satisfied" for educational services ranged from 82.0% (Vocational and Technical Education) downward to 50.0% (After School Tutor), with over half of the services showing a satisfaction rate of 66.7% or higher. These figures hide certain relationships that should be noted.

First, there is the relationship between satisfaction for various educational options from elementary through high school. The level of satisfaction from highest to lowest is as follows: regular school room with resource room (80.0%); special school (day) (78.0%); regular school room (73.1%); homebound education (60.0%); special school (residential) (53.3%). Two inferences are suggested from this ordering. First, integration into regular school must be accompanied by appropriate supports (e.g., resource rooms; special classrooms) to maximize satisfaction. Second, the ordering suggests the contribution of both family and educational integration to satisfaction with services. That is, data suggest that the more similar the home and educational experiences of persons with disabilities are to the

experiences of persons without disabilities, the more satisfied will be the consumer with those services.

**Table 26**

**Satisfaction with Educational Services and Supports**

| | Number of Consumers | Percent of Consumers Satisfied or Very Satisfied | Percent of Consumers Dissatisfied or Very Dissatisfied |
|---|---|---|---|
| A. Pre-Elementary Services | | | |
| Early Intervention | 34 | 82.4 | 2.9 |
| Pre-School | 50 | 76.0 | 8.0 |
| Total Pre-Elementary | 84 | 78.6 | 6.0 |
| B. Regular School Class | | | |
| Regular School Room | 52 | 73.1 | 11.5 |
| Regular School Room and Resource Room | 15 | 80.0 | 13.3 |
| Total Regular School Class | 67 | 74.6 | 11.9 |
| C. Special School Class | | | |
| Special Class in Regular School | 61 | 63.9 | 19.7 |
| Special School (Day) | 41 | 78.0 | 14.6 |
| Special School (Residential) | 15 | 53.3 | 20.0 |
| Total Special School Class | 117 | 66.7 | 17.9 |
| D. Career and Professional Preparation | | | |
| Vocational & Technical Education | 42 | 83.3 | 14.3 |
| Adult Literacy Programs | 13 | 69.2 | 23.1 |
| Post-Secondary Education | 15 | 66.6 | 20.0 |
| Total Career/Professional Preparation | 70 | 77.1 | 17.1 |
| E. Support & Other Educational Services | | | |
| Summer School | 35 | 62.9 | 25.7 |
| Homebound Education | 10 | 60.0 | 10.0 |
| Related Services (e.g., Aide, Attendent) | 31 | 54.8 | 32.2 |
| After School Tutor | 8 | 50.0 | 25.0 |
| Total Support & Other Educational Services | 84 | 58.3 | 26.2 |

A second relationship that should be noted involves the comparison of satisfaction with direct educational services to satisfaction with assistance designed to support educational services. Generally, educational services are highly regarded with satisfaction for direct educational services at 78.6% for pre-elementary services, 74.6% for regular school classes, and 66.7% for special school classes. Services provided to support educational experiences of persons with disabilities fared considerably worse, however. Only 54.8% of consumers were satisfied with support services such as provision of aides or attendants and only 50.0% with after school tutors. Dominant reasons for dissatisfaction included "not receiving enough" and "poor quality." Taken together, these data suggest the need for renewed attention to consumer needs for supportive services aimed at maximizing the effectiveness of direct educational experiences.

The above relationship between direct educational services and support for those services is also highlighted by data on needs for educational services (Table 27). With the exception of vocational and technical education (the need most emphasized by our consumer sample), supportive educational services showed a greater need than direct educational services. This was especially true for short courses such as summer school and related programs (51.9% indicating a need for services) and services such as provision of aides and attendants (32.7% indicating a need for this

service). The most common reasons for not receiving such services were "not available," "not appropriate to needs or person doesn't like the service," and "other reasons."

**Table 27**

**Needs for Educational Services and Supports**

| | Number of Respondents | Percent Indicating Slight or Moderate Need | Percent Indicating Strong, Urgent or Primary Need |
|---|---|---|---|
| A. Pre-Elementary Services | | | |
| Early Intervention | 143 | 2.7 | 10.5 |
| Pre-School | 154 | 1.3 | 19.5 |
| Total Pre-Elementary | 297 | 2.0 | 15.8 |
| B. Career & Professional Preparation | | | |
| Vocational & Technical Education | 166 | 12.7 | 39.2 |
| Adult Literacy Programs | 140 | 7.9 | 12.1 |
| Post-Secondary Education | 139 | 10.1 | 12.2 |
| Total Career/Professional Preparation | 445 | 10.3 | 22.2 |
| C. Support & Other Educational Services | | | |
| Summer School | 160 | 13.8 | 32.5 |
| Related Services (e.g., Aide, Attendent) | 150 | 8.0 | 24.7 |
| After School Tutor | 149 | 8.7 | 14.8 |
| Total Support & Other | 459 | 10.2 | 24.2 |

Generally, the reasons given for not receiving direct educational services were similar except that "not eligible by type or degree of disability" was noted by several consumers. Additionally, "service is too expensive to obtain" was endorsed by consumers in need of post-secondary education.

## Vocational and Other Adult Day Services

This area includes a host of services that become available after adults with developmental disabilities leave the public

school system. These services are aimed at increasing the potential for or to provide assistance in achieving and maintaining employment.

Table 28 separates this range of services into three groupings: (a) services showing a satisfaction rate of above 70.0%, (b) services showing a satisfaction rate between 60.0% and 70.0%, and (c) services showing a satisfaction rate of below 60.0%. Generally, this table indicates greatest

**Table 28**

**Satisfaction with Vocational and Other Adult Day Services**

| | Number of Consumers | Percent of Consumers Satisfied or Very Satisfied | Percent of Consumers Dissatisfied or Very Dissatisfied |
|---|---|---|---|
| A. Above 70.0% Satisfaction | | | |
| Adult Day Services, Developmental | 25 | 88.0 | 4.0 |
| Work Activities/Prevocational | 28 | 82.1 | 7.1 |
| Sheltered Employment (Facility Based) | 32 | 78.1 | 9.4 |
| Work Adjustment | 8 | 75.0 | 12.5 |
| Psychosocial Rehabilitation | 19 | 73.7 | 5.3 |
| B. 60.0-70.0% Satisfaction | | | |
| Adult Day Services, Non-Developmental | 14 | 64.6 | 7.1 |
| Partial Hospitalization | 11 | 63.6 | 0.0 |
| Sheltered Employment (Non Facility Based) | 11 | 63.6 | 18.2 |
| Competitive Employment | 11 | 63.6 | 18.2 |
| C. Below 60.0% Satisfaction | | | |
| On-Site Attendent | 17 | 58.8 | 17.6 |
| Day Treatment | 12 | 58.3 | 0.0 |
| Supported Employment | 7 | 42.9 | 0.0 |
| Job Placement | 19 | 36.8 | 52.6 |
| On-Site Modification | 12 | 33.3 | 33.3 |

satisfaction was for services designed to prepare persons with disabilities for work (e.g., work activities/prevocational;

psychosocial rehabilitation) and for certain supports (i.e., facility-based sheltered employment). Services offering least satisfaction were those designed to directly support obtained employment (e.g., on-site attendant; on-site modification) and certain placement and general supportive activities (e.g., job placement; day treatment). As with the section on educational services, these results suggest that Virginia's service strengths may lie in the teaching of information and skills related to life roles for persons with developmental disabilities. Her weakness may lie in the transition from teaching knowledge to teaching skills. In other words, our weakness appears to be related to our inability to support persons with developmental disabilities in effectively putting into practice the knowledge we teach them. Practically, the inability may be caused by a cluster of ineffective support structures such as aides and on-site work modifications. Job placement is especially a problem, with over half of consumers indicating that they are dissatisfied or very dissatisfied with the services they have received. The most common reasons given for dissatisfaction with placement services included "not receiving enough," "not suited to individual needs," and "poor quality." Reasons given for dissatisfaction with work-site modification included "not receiving enough," and "not suited to individual needs."

Needs for Vocational and Other Adult Day Services are given in Table 29. Strongest needs are expressed for

vocational training and employment services. Weakest needs are indicated for on-site aides or attendants, psychosocial rehabilitation and on-site modification. These ratings are

**Table 29**

**Needs for Vocational and Other Adult Day Services**

| | Number of Respondents | Percent Indicating Slight or Moderate Need | Percent Indicating Strong, Urgent or Primary Need |
|---|---|---|---|
| A. Services Needed Strongly, Urgently, or Primarily by Over 20% of Respondents | | | |
| Vocational Training Services | 161 | 12.4 | 41.6 |
| Employment Services | 152 | 16.4 | 30.9 |
| Habilitation | 137 | 7.2 | 25.5 |
| Adult or Day Care | 141 | 6.4 | 22.0 |
| B. Services Needed Strongly, Urgently, or Primarily by Fewer Than 20% of Respondents | | | |
| On-Site Aide or Attendent | 166 | 3.0 | 18.7 |
| Psychosocial Rehabilitation | 142 | 9.9 | 13.4 |
| On-Site Modification | 134 | 9.0 | 12.7 |

somewhat deceptive, however. These needs are rated lower because they are needed by some groups but not others. When sub-populations are considered, strong needs are evidenced for on-site aides or attendants (physical and cognitive), psychosocial rehabilitation (cognitive and mental illness), and on-site modifications (physical). Virtually all categories, then, of vocational and adult day services show strong needs, some for persons with all types of disabilities and some for specific sub-populations. Reasons for not receiving services were most often given as "not appropriate to need or person doesn't like the service," "not available in the area," and "other reason."

## Health Services

These services include general medical services for evaluating the health status of individuals, for identifying and correcting acute conditions, for managing medical aspects of chronic handicapping conditions, and for treating other medical conditions.

Table 30 presents findings on satisfaction with health services. Generally, a consistent high degree of satisfaction is found with medical services. Exceptions are for certain services related to financial welfare (i.e., private health insurance; payment for or provision of medical equipment) and genetic counseling. The most common reason for dissatisfaction related to financial services was "too expensive."

**Table 30**

**Satisfaction with Health Services**

| | Number of Respondents | Percent Indicating Slight or Moderate Need | Percent Indicating Strong, Urgent or Primary Need |
|---|---|---|---|
| General Health Services | 156 | 85.3 | 8.3 |
| Payment for Medication | 107 | 85.0 | 8.4 |
| Medicaid (Medical Care) | 93 | 84.9 | 6.5 |
| Dental Services | 150 | 83.3 | 10.7 |
| General/Specific Hospitals | 85 | 78.8 | 15.3 |
| Emergency Health Services | 58 | 77.6 | 13.8 |
| Health Insurance (Private) | 134 | 65.7 | 22.4 |
| Payment for Medical Equipment | 78 | 65.4 | 24.4 |
| Genetic Counseling | 22 | 63.6 | 13.6 |

Table 31 shows level of need expressed for health supports and services. When we consider ratings of strong, urgent or primary needs, the top three needs are health

**Table 31**

**Needs for Health Supports and Services**

| | Number of Respondents | Percent Indicating Slight or Moderate Need | Percent Indicating Strong, Urgent or Primary Need |
|---|---|---|---|
| A. Financial Supports | | | |
| Health Insurance (Private) | 195 | 17.9 | 52.3 |
| Payment of Medication | 184 | 17.4 | 43.5 |
| Payment for or Provision of Medical Equipment | 182 | 13.2 | 39.6 |
| B. Medical Services | | | |
| General Medical Services | 211 | 45.5 | 34.6 |
| Dental Services | 216 | 48.1 | 32.9 |

insurance (private) (52.3%), payments for medication (43.5%), and payment for or provision of medical equipment (39.6%). This suggests that Virginia's current consumer issues related to medical care may be "pocketbook issues" and probably reflect the devastating cost of disability to families detailed so well in the literature on disability. The dominant reasons for not receiving services in these areas was given as "too expensive."

## Transportation Supports and Services

These services are designed to transport consumers from their residence to work, services, recreation, education, and other activities of daily life and to return them to their home. Supports needed for adequate transportation are also included in this category.

Table 32 provides information on satisfaction with transportation supports and services. Generally, satisfaction is high. It is highest (76.9% of respondents satisfied) for routine activities that occur on a daily basis (e.g., work, school). There is a slight drop in satisfaction (72.2%) when transportation services are required to respond to non-routine services or activities (e.g., medical appointments; shopping). There is again a drop in satisfaction (69.6%) when transportation is required for leisure time on weekdays. The lowest level of satisfaction (68.1%) was expressed toward transportation services for leisure time on weekends. Three

**Table 32**

**Satisfaction with Transportation Supports and Services**

| | Number of Respondents | Percent Indicating Satisfied or Very Satisfied | Percent Indicating Dissatisfied or Very Dissatisfied |
|---|---|---|---|
| A. Transportation Services | | | |
| To and From Work, School, and Day Activities | 208 | 76.9 | 16.3 |
| To and From Non-Daily Services and Activities | 162 | 72.2 | 21.6 |
| For Leisure Time (weekdays) | 158 | 69.6 | 24.1 |
| For Leisure Time (weekends) | 160 | 68.1 | 26.9 |
| B. Transportation Supports | | | |
| Transportation Training (e.g., driver's education; use of public transportation) | 33 | 60.6 | 27.3 |
| Vehicle Modification | 27 | 59.3 | 18.5 |

themes seem to determine satisfaction with transportation services: (a) whether the activity requiring transportation occurs on a routine, daily basis, (b) whether the

transportation is for "necessary" life activities (e.g., medical appointments) or for leisure, and (c) whether the request for transportation is for weekends or weekdays. Satisfaction with transportation training and vehicle modification, is a bit lower.

Needs for transportation supports and services are given in Table 33. Generally needs reflect a similar relationship to satisfaction. Needs for routine, daily transportation are lowest among the categories surveyed. Transportation for non-routine, weekend and leisure pursuits shows twice the number of consumers indicating strong, urgent or primary needs in

**Table 33**

**Needs for Transportation Supports and Services**

| | Number of Respondents | Percent Indicating Satisfied or Very Satisfied | Percent Indicating Dissatisfied or Very Dissatisfied |
|---|---|---|---|
| A. Transportation Services | | | |
| To and From Work, School and Day Activities | 243 | 7.8 | 26.7 |
| To and From Non-Daily Services and Activities | 229 | 11.8 | 55.5 |
| For Leisure Time (weekdays) | 234 | 17.9 | 50.9 |
| For Leisure Time (weekends) | 233 | 17.6 | 51.5 |
| B. Transportation Supports | | | |
| Transportation Training (e.g., driver's license; use of public transportation) | 186 | 4.3 | 22.0 |
| Vehicle Modification | 189 | 4.2 | 18.5 |

each of these areas. Most common reasons for not receiving services in these areas were similar across types of needs and were (in order of prevalence) "service is not available in the

area," "service is too expensive to obtain," "not appropriate to needs or person doesn't like the service," and "other reasons."

There was a lower level of need for transportation supports. Just under a quarter (22.0%) of consumers responding indicated a strong, urgent or primary need for transportation training. Among adults with physical disabilities, however, this figure was 46.7%. Similarly, only 18.5% of respondents indicated a strong, urgent, or primary need for vehicle modification. The figure for persons with physical disabilities was 64.7%. These data suggest that the relatively low need for transportation supports indicated by the overall sample hide a very strong need in this area for persons with physical disabilities.

Individual Support Services

This area includes those supports and services designed to minimize handicapping behavioral, physical, and related conditions to allow persons with developmental disabilities to function at or near the levels of persons without disabilities. A broad range of services is included. Satisfaction with these supports and services is presented in Table 34. Needs for these services are represented in Table 35. Because of the complexity of this array of supports and services, the array will be divided into several parts: (a) respite care, (b) mental health and behavioral management, (c)

## Table 34

## Satisfaction with Individual Support Services

| | Number of Respondents | Percent Satisfied or Very Satisfied | Percent Dissatisfied or Very Dissatisfied |
|---|---|---|---|
| A. Respite Care | | | |
| In Home | 40 | 45.0 | 35.0 |
| Out of Home | 31 | 48.4 | 32.3 |
| B. Mental Health and Behavioral Management | | | |
| Behavior Management | 42 | 54.8 | 4.8 |
| Mental Health Counseling | 56 | 67.9 | 19.6 |
| C. Health-Related | | | |
| Physical Therapy | 87 | 69.0 | 17.2 |
| Occupational Therapy | 79 | 64.6 | 19.0 |
| D. Human Resources | | | |
| Attendent Care | 26 | 73.1 | 7.7 |
| Home Health Aide/Visiting Nurse | 20 | 70.0 | 5.0 |
| Homemaker/Chore Services | 7 | 71.4 | 0.0 |
| Companion/Friend-Advocate Program | 17 | 41.2 | 35.3 |
| E. Community-Related | | | |
| Community Living Assistance or Training | 31 | 71.0 | 12.9 |
| Self-Help/Support Groups | 68 | 80.9 | 4.4 |
| Community Support Services | 40 | 62.5 | 17.5 |
| F. Financial | | | |
| Income Assistance (i.e., SSI) | 93 | 72.0 | 19.4 |
| Food Assistance/Food Stamps | 34 | 47.1 | 26.5 |
| Financial Management Assistance | 22 | 54.5 | 36.4 |
| G. Other | | | |
| Protective/Legal Services | 27 | 70.4 | 18.5 |
| Communication & Language Services | 95 | 54.7 | 25.3 |
| Adaptive Equipment/Assistive Devices & Training | 58 | 74.1 | 19.0 |
| Cooking/Meals on Wheels | 5 | 60.0 | 0.0 |

## Table 35

## Needs for Individual Support Services

| | Number of Respondents | Slight or Moderate Need | Strong, Urgent or Primary Need |
|---|---|---|---|
| A. Respite Care | | | |
| In Home | 187 | 14.4 | 27.3 |
| Out of Home | 173 | 14.5 | 25.4 |
| B. Mental Health and Behavioral Management | | | |
| Behavioral Management | 175 | 16.0 | 17.7 |
| Mental Health Counseling | 184 | 14.1 | 26.1 |
| C. Health-Related | | | |
| Physical Therapy | 180 | 8.9 | 37.8 |
| Occupational Therapy | 179 | 10.6 | 34.1 |
| D. Human Resources | | | |
| Attendant Care | 165 | 5.5 | 15.8 |
| Home Health Aide/Visiting Nurse | 155 | 6.5 | 6.5 |
| Homemaker/Chore Services | 159 | 6.3 | 15.7 |
| Companion/Friend-Advocate Program | 174 | 13.8 | 32.8 |
| E. Community-Related | | | |
| Community Living Assistance or Training | 161 | 7.5 | 31.3 |
| Self-Help/Support Groups | 175 | 22.3 | 39.4 |
| Community Support Services | 180 | 16.7 | 35.6 |
| F. Financial | | | |
| Income Assistance (i.e., SSI) | 185 | 15.1 | 47.6 |
| Food Assistance/Food Stamps | 165 | 7.9 | 23.6 |
| Financial Management Assistance | 170 | 12.4 | 28.8 |
| G. Other | | | |
| Protective/Legal Services | 170 | 23.5 | 17.1 |
| Communication & Language Services | 192 | 10.4 | 47.9 |
| Adaptive Equipment/Assistive Devices | 169 | 8.3 | 30.2 |
| Cooking/Meals on Wheels | 154 | 4.5 | 11.7 |



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health-related, (d) human resources, (e) community-related, (f) financial and (g) other.

**Respite care**. Respite care, both in-home and outside the home shows a relatively low level of satisfaction and high rate of dissatisfaction from the consumers of our survey. While almost half indicated that they were satisfied or very satisfied, about a third showed dissatisfaction with these services, an unusually high figure. This is unfortunate since about four of every ten consumers surveyed indicated some need for respite care. This need was particularly acute among youth with cognitive disabilities.

**Mental health and behavioral management**. Satisfaction with mental health counseling and behavioral management services, the two services in this category, are somewhat different. Over half (54.8%) of persons who have experienced behavioral management services (mostly persons with cognitive disabilities) characterized themselves as satisfied or very satisfied while only 4.8% indicated they were dissatisfied or very dissatisfied. In contrast, 67.9% of persons receiving mental health counseling were satisfied while 19.6% were dissatisfied. When adults were broken into disability categories, persons with cognitive disabilities showed greater satisfaction with mental health counseling services than with behavioral management services. Satisfaction of other groups using high levels of mental health services (i.e., sensory and mental illness) was even higher. Persons with physical

disabilities showed a relatively low usage rate for mental health services.

As with satisfaction, needs also showed a difference for these services. Behavioral management assistance and training was indicated as a strong, urgent or primary need by 17.7% of respondents while 26.1% of respondents indicated a comparable need for mental health counseling. These statistics are deceptive, however, since behavioral management needs are limited predominantly to persons with cognitive disabilities while mental health counseling services are indicated by three disability categories (i.e., cognitive, sensory, mental health). If we consider cognitive disabilities alone, 40.6% of adults indicated a need for behavioral management services and 44.1% for mental health counseling. We conclude that both behavioral management and mental health counseling services show significant needs but for different populations of persons with disabilities.

Health-related. Health-related supports and services included physical therapy, occupational therapy and other services related to each. Generally, health-related services were favorably considered with 69.0% and 64.6% of consumers either satisfied or very satisfied with physical therapy and occupational therapy, respectively. A relatively high level of need was expressed for these services with over a third of consumers responding to these items indicating needs in these health-related areas.

**Human resources**. The human resources area includes four types of service and support: (a) attendant care, (b) home health aides and visiting nurses, (c) homemaker/chore service providers, and (d) companion, friend or advocate projects. General satisfaction with these services and supports is rather high with about seven of every ten consumers who receive services indicating satisfaction (The exception to this statement was for companion, friend, and advocate projects which will be reviewed below). Some trends in incidence of use and satisfaction indicated differences across age and disability categories. Generally, more members of our sample with cognitive disabilities received these services than did other groups. The exception to this was for attendant care where equal numbers of persons with cognitive disabilities and physical disabilities were served. Persons with cognitive disabilities tended to be satisfied with these services. Persons with other disabilities tended to be less satisfied. This was especially true for persons with sensory disabilities.

Provision of these services was also related to age. Approximate equal numbers of youth and adults received home health aides or visiting nurses and assistance from companion, friend or advocate projects. In contrast, attendant care and homemaker /chore services were primarily used by adults.

The exception to the generally favorable ratings, as noted above, was for assistance from companion, friend, and

advocate projects where only 41.2% of consumers indicated satisfaction and 35.3% indicated dissatisfaction. As with other human resources categories, there was a marked tendency for persons with cognitive disabilities to be satisfied and for persons with other types of disabilities to be dissatisfied. The most common reason given for dissatisfaction was "not receiving enough."

Our data indicate that needs for most of these services were relatively low with fewer than 20% of consumers reporting strong, primary or urgent needs. The exception to this trend was for assistance from companion, friend or advocacy projects where 32.5% of consumers indicated a strong, primary, or urgent need. This result should be viewed from the perspective of the consumers' limited opportunities for social contact and community integration detailed elsewhere in this report (see Chapter 6, Community Living and Integration). Level of need for these services also showed important differences across disability categories and ages. Over 30% of consumers with physical disabilities indicated strong, primary or urgent needs for attendant care. Over a third (36.7%) of adult respondents to the survey indicated a strong, primary, or urgent need for homemaker or chore services. Needs for homemaker and chore services were divided fairly evenly across disability categories (with the exception of mental illness which had too few respondents to draw a conclusion).

**Community-related**. Community-related services and support fell into three areas: (a) community living assistance or training, (b) self-help and support groups, and (c) community support services. Satisfaction with this cluster of services varied from moderate to very high. A fairly high level of satisfaction was expressed for community living assistance or training projects with 71.0% of consumers indicating that they were satisfied or very satisfied with these services. About two-thirds of persons receiving these services were adults and about one-third were youth. Overall, youth respondents indicated a slightly lower level of satisfaction with these services than did adults. Satisfaction with community support services would best be characterized as moderate with 62.5% of those responding indicating satisfaction with these services. Here too, data suggest that youth are generally less satisfied with these services than are adults. Satisfaction with self-help and support groups was highest among all services and supports listed under Individual Support Services with 80.9% indicating satisfaction with such involvement.

Each of these areas showed relatively high levels of need with around a third of respondents indicating a strong, primary, or urgent need for each type of support or service (i.e., community living assistance or training, 31.3%; community support services, 35.6%; self-help/support groups, 39.4%). Persons with cognitive disabilities and mental

illness generally had greater needs for community living assistance or training and community support services than did persons with other types of disabilities. Dominant reasons for not receiving these services were given as "service is not available in the area," "not appropriate to needs or person does not like the service," and "other reasons." Needs for self-help and support groups were similar across all disability categories. Dominant reasons for not receiving the service included "not available in the area," "not appropriate to needs of person or person does not like the service," "other reason," and "person did not know the service existed."

**Financial**. Financial and related services and supports included three areas: (a) income assistance (i.e., SSI), (b) food assistance/food stamps, and (c) financial management assistance. These services and supports showed low to high levels of satisfaction. Almost three-fourths (72.0%) of consumers receiving income assistance characterized themselves as "satisfied" or "very satisfied." When satisfaction was broken down by disability category, persons with cognitive disabilities displayed a greater satisfaction and persons with physical disabilities less satisfaction than persons with other types of disabilities. The dominant reason for dissatisfaction was "not receiving enough." In contrast to income assistance, other financial services and supports showed considerably lower levels of satisfaction. Only about

half of persons receiving food assistance/food stamps (47.1%) or financial management assistance (54.5%) indicated they were satisfied with the service. The dominant reason for dissatisfaction with these services and supports was "not receiving enough."

Relatively high levels of need were expressed for financial assistance with about a fourth of all consumers expressing strong, primary, or urgent needs for food assistance/food stamps (23.6%) and financial management services (28.8%) and almost half for income assistance (47.6%). Consumers with mental illness expressed the greatest need for assistance in each of these service and support categories. Consumers with cognitive disabilities also expressed a strong need for financial management assistance. The dominant reason for not receiving income assistance and food assistance/food stamps was "not eligible because of income or means." The primary reasons for not receiving financial management assistance were "person did not know the service existed" and "other reason."

Other. This category is a catch-all for services and supports not fitting neatly into other categories. This includes (a) protective or legal services, (b) communication and language services, (c) adaptive equipment, assistance devices and training, and (d) cooking and meals on wheels. Satisfaction with these services was moderate to high. Almost three-quarters (70.4%) of persons receiving protective and

legal services indicated that they were satisfied with such services. About one in every six (17.6%) consumers had a strong, primary, or urgent need for protective or legal services at the time of the survey, a need most prevalent among persons with cognitive disabilities.

Satisfaction with communication and language services was considerably lower with only 54.7% of consumers who had received these services indicating that they were satisfied with them. Use of these services was particularly strong among persons with sensory disabilities but other groups (i.e., physical; cognitive) showed significant use as well. Of the disability categories, persons with cognitive disabilities showed least satisfaction with these services. The dominant reason for dissatisfaction was given as "not suited to individual needs." Dissatisfaction with these services was particularly acute among youth. A very high level of need for communication and language services was indicated by respondents to our survey. The reader is reminded of the very high incidence of speech impairment judged as a secondary disability in our sample (see Tables 5 and 6) for both youth and adults. Current expressed needs were particularly strong for persons with cognitive and physical disabilities and for youth with almost 60% of the youth of our sample indicating such a need. The most common reason for youth not receiving these services was given as "service that is available is not appropriate to needs or

person doesn't like the service." The most common reasons for adults were "too expensive" and "other reason."

In contrast to communication and language services, services related to adaptive equipment and assistive devices and training were generally seen as satisfying, with 74.1% of consumers using these services indicating that they were "satisfied" or "very satisfied". Most of these services were used by persons with physical or sensory disabilities. Satisfaction for each of these disability categories was about the same. The primary reason for dissatisfaction was given as "too expensive." Needs for these services were also high with almost a third (30.2%) of consumers indicating a strong, primary, or urgent need. For persons with physical and sensory disabilities, the percentage of persons with strong, primary, or urgent needs was 58.1% and 46.3%, respectively. The need was found to be especially strong among youth. The most common reasons for not receiving these services were "not appropriate to needs or person doesn't like the service" (youth), and "too expensive", or "other reason" (adult).

Services related to cooking and meals on wheels garnered moderately high satisfaction ratings. Six of every ten (60.0%) consumers who had received these services indicated that they were "satisfied" or "very satisfied." Of the few persons receiving these services, most had cognitive or sensory disabilities. All were adults. Generally, persons with sensory disabilities were least satisfied with these

services. Among respondents to our survey, only 11.7% expressed a strong, primary, or urgent need for these services. Expressed needs for services, in order from greatest to least, were for persons with cognitive, sensory, and physical disabilities.

## Caregiver Support Services

This area includes those supports and services designed to have an indirect impact on consumers by providing assistance to caregivers that will allow them to provide improved care to persons with developmental disabilities. A broad range of services is included. Satisfaction with these supports and services is presented in Table 36. Needs for these supports and services are presented in Table 37. The array of supports and services has been divided into several parts: (a) respite care, (b) day care services, (c) human resources, (d) mental health and behavioral management services, (e) educational services, and (f) other.

**Respite care**. As with respite care for consumers, a relatively low proportion of consumers expressed satisfaction with caregiver respite care, whether in-home (46.2%) or out-of-home (53.6%). Most of this respite care was provided for the caregivers of persons with cognitive and physical disabilities. Satisfaction levels for these two groups were about the same. When age is considered, respondents were

**Table 36**

**Satisfaction with Caregiver Support Services**

| Caregiver Support Services | Number of Respondents | Percent Satisfied or Very Satisfied | Percent Dissatisfied or Very Dissatisfied |
|---|---|---|---|
| A. Respite Care | | | |
| In Home (recently) | 26 | 46.2 | 41.0 |
| Out of Home (recently) | | 53.6 | 39.3 |
| B. Day Care | | | |
| Child | 23 | 34.8 | 47.8 |
| Adult | 5 | 60.0 | 20.0 |
| C. Human Resources | | | |
| Homemaker/Chore Services | 8 | 62.5 | 12.5 |
| Family Support Group | 64 | 75.0 | 14.1 |
| D. Mental Health and Behavioral Management Services | | | |
| Behavioral Management Assistance/ Training | 27 | 44.4 | 33.3 |
| Family Counseling (recently) | 29 | 58.6 | 27.6 |
| E. Educational Services | | | |
| Parent Training (recently) | 36 | 69.4 | 22.2 |
| Family Education (recently) | 25 | 64.0 | 24.0 |
| F. Other | | | |
| Genetic Screening and/or Counseling (recently) | 10 | 60.0 | 20.0 |
| Family Cash Assistance | 18 | 44.4 | 33.3 |
| Special Needs Adoption | 8 | 75.0 | 12.5 |

considerably less satisfied for services to caregivers of youth than when services were provided to caregivers of adults.

Two reasons for dissatisfaction were dominant: "not receiving enough" and "too expensive." Despite the relatively low levels of satisfaction, the services reflected some of the strongest caregiver needs noted by our respondents. Fully 40.1% and 31.6% of respondents indicated strong, primary, or urgent needs for in-home and out-of-home respite care,

## Table 37

## Needs for Caregiver Support Services

| | Number of Respondents | Slight or Moderate Need | Strong, Urgent or Primary Need |
|---|---|---|---|
| A. Respite Care | | | |
| In Home | 167 | 12.6 | 40.1 |
| Out of Home | 155 | 14.8 | 31.6 |
| B. Day Care | | | |
| Child | 146 | 8.2 | 22.6 |
| Adult | 136 | 4.4 | 15.4 |
| C. Human Resources | | | |
| Homemaker/Chore Services | 136 | 6.6 | 13.2 |
| Family Support Group | 162 | 18.5 | 36.4 |
| D. Mental Health and Behavioral Management Services | | | |
| Behavioral Management Assistance and Training | 147 | 14.3 | 16.3 |
| Family Counseling | 156 | 25.6 | 17.3 |
| E. Educational Services | | | |
| Parent Training | 156 | 23.7 | 16.0 |
| Family Education | 154 | 18.2 | 15.6 |
| F. Other | | | |
| Genetic Screening and/or Counseling | 142 | 10.6 | 9.9 |
| Family Cash Assistance | 146 | 15.1 | 14.4 |
| Special Needs Adoption | 0 | 0.0 | 0.0 |

respectively. Need varied greatly across disability categories with respondents indicating 50% or more of persons with physical disabilities or mental illness in need of these services. About a quarter of persons with cognitive disabilities and a tenth of persons with sensory disabilities also indicated a need in this area. Needs for these services were considerably greater for caregivers of children than for caregivers of adults. Dominant reasons for not receiving these services were given as "too expensive" and "service not available in the area."

**Day care**. Data indicated considerable differences in

60.0% of respondents were satisfied with adult day care, only 34.8% were satisfied with day care for children. Dissatisfaction was especially high among persons with physical disabilities. Primary reasons for dissatisfaction included "too expensive," "not suited to individual needs", and "any other reason." Needs for day care services are significant but considerably less than for respite care services with 22.6% and 15.4% of respondents indicating strong, primary or urgent needs for child and adult services, respectively. Day care needs for children were especially high among persons with physical disabilities. Needs for adults were highest among persons with mental illness. Reasons for not receiving services were different for different ages and disabilities. For children, dominant reasons for not receiving services were given as "not appropriate to needs," "not available in the area," "too expensive," and "other reason." Additionally, several persons with cognitive disabilities responded "not eligible by type or degree of disability." Reasons for not receiving adult day care were simpler: "not appropriate to needs or person doesn't like the service" or "other reason."

Human resources. Two types of human resources were listed in the survey section for caregiver support services: (a) homemaker/chore services and (b) family support groups. Each of these supports had a relatively high level of satisfaction with 62.5% of persons receiving homemaker or

chore services and 75.0% of persons involved in family support groups indicating "satisfied" or "very satisfied" on the survey. Currently, very few persons with developmental disabilities were receiving homemaker or chore services. A considerably greater proportion were involved in family support groups. Data on family support groups indicated that satisfaction was different across disability categories. Caregivers of persons with physical and sensory disabilities showed a high level of satisfaction with these groups (100% for sensory; 76.9% for physical) while the satisfaction of caregivers for persons with cognitive disabilities was considerably lower (57.7%). There was insufficient involvement of caregivers of persons with mental illness (i.e., only two caregivers of persons with mental illness were involved in support groups) to conduct an analysis with this category. The most common reason given for dissatisfaction with caregiver support groups were "other reason", "poor quality," and "not suited to individual needs." Among our respondents, relatively low levels of need were expressed for homemaker and chore services (13.2% indicated strong, primary or urgent needs). Expressed needs were relatively constant across disability categroies. In contrast, a high level of need was expressed for caregiver support groups. Over a third (36.4%) of those responding indicated a need for involvement of their caregiver in such groups, a level of need similar to that of consumers for involvement in self-help or support

groups. Needs were particularly strong for caregivers of persons with sensory disabilities and mental illness and for caregivers of children. The most common reason given for not receiving these services were "not available in the area."

**Mental health and behavioral management services**. Two types of services and supports fall into this category: (a) behavioral management services, and (b) family counseling. Level of satisfaction with these services can best be characterized as moderate to low. Less than half (44.4%) of consumers receiving behavioral management services indicated that they were satisfied or very satisfied while 33.3% noted that they were dissatisfied or very dissatisfied with these services. While over half of these services went to youth between the ages of six and twenty, satisfaction was about the same for services to caregivers of youth and adults. Most of these services went to persons with cognitive and physical disabilities though the proportion of our small sample of persons with mental illness was also rather high. Among these groups, dissatisfaction with services was particularly high for persons with physical disabilities and mental illness. The most common reasons for dissatisfaction included "not receiving enough" and "not suited to individual needs." Needs for these services were low with only 16.3% indicating a strong, primary or urgent need. Needs for these services were highest for caregivers of persons with mental illness and cognitive disabilities. From the perspective of age, limited

data suggest that need is highest for caregivers of children aged 0-5, and then decreases progressively throughout the lifespan until age 61 when it again appears to increase.

Family counseling for caregivers showed a higher level of satisfaction with 58.6% indicating that they were "satisfied" or "very satisfied" with these services and 27.6% indicating dissatisfaction. For our survey sample, family counseling was six times more likely to occur for caregivers of youth than for caregivers of adults. Most family counseling for caregivers occurred when the persons for whom they cared were between ages six and twenty. The primary reason given for dissatisfaction was "not receiving enough." As with behavioral management assistance and training, data on family counseling indicated a relatively low level of need. Strongest needs were expressed for caregivers of our small samples of persons with mental illness and for persons over the age of 61. Dominant reasons for not receiving these services included "other reason", "too expensive", and "not appropriate to needs of person or doesn't like the service."

**Educational services**. Services in this category are of two kinds: (a) parent training, and (b) family education. Satisfaction with both services was relatively high. Over two-thirds (69.4%) of persons experiencing parent training indicated satisfaction with these services. Satisfaction was especially high among persons with sensory disabilities and appeared especially low among persons with cognitive

disabilities. Among those dissatisfied with this service "not receiving enough" was the reason most often given. As with mental health and behavioral management services, the expressed need for parent training was relatively low with only 16.0% of our sample indicating a strong, primary or urgent need. About one in four (27.3%) of parents of children with developmental disabilities between birth and age five were found to have strong, primary, or urgent needs in this area, however. This was particularly true for parents of children with mental illness. Dominant reasons for not receiving these services included "other reason", "not available in this area," and "not appropriate to needs or person doesn't like the services."

Results for family education were somewhat similar with 64.0% of consumers noting their satisfaction with these services. These services appear to be most commonly used by persons with sensory disabilities and it is this disability category that shows the greatest satisfaction with these services. These services are most prevalent for caregivers of school-age youth. Data on needs suggested a relatively low level of need for these services with 15.6% of adult respondents expressing a strong, primary, or urgent need. Primary need for these services were among our small sample of persons with mental illness and among persons with sensory disabilities. Data suggest that needs exist predominantly during the school-age years. Dominant reasons given for not

receiving these services included "other reason" and "not available in the area."

**Other**. Three types of services or supports did not fit neatly into the above categories. These included: (a) genetic screening and/or counseling, (b) family cash assistance, and (c) special needs adoption.

Services to caregivers involving genetic screening and counseling were somewhat low with 60.0% indicating they were either "satisfied" or "very satisfied" with these services. Most of these services were provided to members of our sample with cognitive or physical disabilities and to caregivers of children. Data were insufficient for further analysis on these services. Relative to needs, fewer than one in ten (9.9%) consumers indicated a need for these services. Most strong, primary, or urgent needs were expressed by persons with cognitive and physical disabilities. The dominant reasons for not receiving these services included "other reasons", "not appropriate to needs or person doesn't like the services," and "person did not know the service existed."

Eighteen members of our sample received family cash assistance. This type of service showed a rather low level of satisfaction (i.e., 44.4% indicated they were "satisfied" or "very satisfied"). A third noted that they were "dissatisfied" or "very dissatisfied." Most of these services are currently provided to persons with physical and cognitive disabilities and for families with school-age children. The

dominant reason for dissatisfaction was "not receiving enough." Family cash assistance also showed a relatively low level of need among the members of our sample with only 14.4% noting a strong, primary, or urgent need. Strongest needs for family cash assistance were for persons in two disability categories, physical and cognitive. Results suggested that greatest needs for these caregiver services occur for the first five years after birth, then gradually decrease throughout childhood and adolescence. Dominant reasons given for not receiving these services included "not eligible because of income or means" and "not available in the area."

Eight members of our sample had received special needs adoption services. These services were among the highest ranked services for caregivers with 75.0% "satisfied" or "very satisfied." Most of these services were provided to caregivers of consumers with physical or cognitive disabilities. "Not suited to individual needs" was the reason given most often for dissatisfaction with these services. No questions were asked on the survey on needs for special adoption services.

## Satisfaction with Select Agencies and Programs

Information was also requested on degree of experience and satisfaction with certain state and federal agencies and programs. Data from these questions are presented in Table 38.

## Table 38

## Experience, Satisfaction and Dissatisfaction of Consumers with Services Provided by Select Agencies and Programs

| Agency/Program | No Experience | | Received Services: Satisfied | | Received Services: Dissatisfied | | Satisfied Among Persons Who Received Services |
|---|---|---|---|---|---|---|---|
| | Number | Percent | Number | Percent | Number | Percent | Percent |
| Aid to Families with Dependent Children (AFDC) | 279 | 93.0 | 8 | 2.8 | 4 | 1.3 | 66.7 |
| Dept. of Rehabilitative Services (DRS) | 152 | 50.0 | 92 | 30.3 | 31 | 10.2 | 74.8 |
| Education (Special or Regular) | 38 | 12.7 | 206 | 68.9 | 49 | 16.4 | 80.8 |
| Medicaid (Dept. of Medical Assistance Services) | 167 | 54.8 | 105 | 34.4 | 14 | 4.3 | 88.2 |
| Dept. of Mental Health, Mental Retardation and Substance Abuse Services (MHMRSAS) | 169 | 56.0 | 97 | 32.1 | 20 | 6.6 | 82.9 |
| Independent Living Centers (CIL) | 250 | 82.8 | 27 | 8.9 | 9 | 3.0 | 75.0 |
| Supplemental Security Income (SSI) | 154 | 50.3 | 105 | 34.3 | 25 | 8.2 | 80.8 |
| Social Security Disability Income (SSDI) | 224 | 73.4 | 61 | 20.0 | 5 | 1.6 | 92.4 |
| Maternal and Child Health (MCH) | 285 | 95.0 | 13 | 0.7 | 0 | 0.0 | 100.0 |
| Children's Specialty Services | 253 | 84.3 | 30 | 10.0 | 8 | 2.7 | 78.9 |
| Community Mental Health Services | 210 | 70.2 | 62 | 20.7 | 10 | 3.3 | 86.1 |
| HUD Section 8 Rent Certificate | 256 | 87.1 | 23 | 7.8 | 1 | 0.3 | 95.8 |

Two insights are apparent from this table. First, with the exception of the Department of Education, no agency or programs play a dominant role for persons with developmental disabilities. About 87% of consumers had had contact with the Department of Education. Most of this contact, we may assume, was in the early years of life. Among members of our sample, no other agency or program had provided services for more than half of our sample though four agencies or programs (e.g., Department of Rehabilitative Services; Department of Medical Assistance Services (Medicaid); Department of Mental Health, Mental Retardation, and Substance Abuse Services; Supplemental Security Income) showed a considerably broader degree of contact than did the others. These findings are supportive of results reported elsewhere that Virginia's service system is characterized by services provided by a myriad of state and federal agencies. Most such service systems require a high degree of cooperation and coordination for success. Most agencies supply services to only a small proportion of persons with developmental disabilities.

Second, satisfaction with agencies and programs varied considerably. Generally, agencies and programs offering financial supports were evaluated more positively than were those that offer a broader range of services. Figure 8 shows this relationship by grouping together agencies and programs where 90% or more persons were satisfied, those where 80% to 90% were satisfied, and those where fewer than 80% of

**Figure 8**

**Level of Satisfaction with Select Agencies and Programs**

| | High Satisfaction (Above 90% Satisfied) | Moderate Satisfaction (80% - 90% Satisfied) | Low Satisfaction (Below 80% Satisfied) |
|---|---|---|---|
| A. Services | 1. Maternal & Child Healthcare | 1. Community Mental Health<br>2. Mental Health, Mental Retardation & Substance Abuse Services | 1. Children's Specialty Services<br>2. Rehabilitative Services<br>3. Independent Living Centers |
| B. Financial Support | 1. HUD Section 8 Rent Certificate<br>2. Social Security Disability Income (SSDI) | 1. Medical Assistance Services (Medicaid)<br>2. Supplemental Security Income (SSI) | 1. Aid to Families with Dependent Children (AFDC) |

participants were satisfied. This finding, suggesting the importance of financial supports to the lives of Virginia's consumers, is not surprising given the emphasis on financial needs found on various measuring indices throughout this report. It should also be noted that, generally, there is a relatively high degree of satisfaction with Virginia's network of service agencies and programs.

## Summary on Life Supports and Services

In Chapter 3, we stressed the functional limitations characterizing four disability groups. We emphasized that for persons with developmental disabilities to be independent, integrated into their communities, and productive, individualized sets of supports and services were required.

"Laundry lists" of what is needed and who needs it are always dull reading and Chapter 4 is no exception. There is

"Laundry lists" of what is needed and who needs it are always dull reading and Chapter 4 is no exception. There is always the tendency to pass over such text quickly and go on to something more engaging. In the case of this report, that would be an error. For embedded within these pages is a picture of satisfaction with and needs for services and supports that holds promise of changing lives of shadow into lives of substance.

To analyze needs for each of the four disability categories would be to adopt the current service system politics in Virginia. It would be to implicitly suggest that satisfactory service systems can adequately be built around categories of disabilities. We will not do that. We, instead, suggest that the full range of services should be available to all persons with developmental disabilities but should be assigned on the basis of case-by-case need.

Having said all this, evaluation of supports and services is still quite important. As we began reviewing our satisfaction and needs data on supports and services, we found that our data fell rather naturally into three groups: (a) causes for celebration, (b) causes on the right track but not there yet, and (c) causes for concern. Causes for celebration were those where 66% or more consumers indicated satisfaction and where fewer than 25% of consumers indicated a strong, primary, or urgent need. Data on these supports and services indicated that our sample was generally satisfied and was

receiving these supports and services in about the right quantity. In other words, quality and quantity gave cause for celebration. A second set of supports and services appeared to be "on the right track but not there yet." These supports and services indicated a high degree (over 66%) of consumers who received them as satisfied but with 25% or more consumers indicating a need. In other words, quality was good but there was not enough of the support or service to go around. A third set of supports and services were a cause of concern. These showed fewer than 66% of consumers satisfied and indicated 25% or more of consumers had a need for these supports or services. For these, neither quality nor quantity was judged adequate. While not all supports or services fell naturally into these categories, most did. The categories and their supports and services are presented in Figure 9. Careful review of this figure suggests four dominant areas of emphasis: (a) concerns related to case coordination services, (b) concerns related to financial matters, (c) concerns related to personal independence, and (d) concerns related to social and community integration.

**Case coordination services**. While the quality of assessment and plan development, case management, and information and referral services was seen as high, our data indicated that there remains a high level of need for these services among members of our sample. This need suggests additional funding for an increase in quantity of services may

be appropriate at this time. Case coordination services aim to assist consumers to better access and use the complex service system available to them. Most consumers view this as a needed service.

**Financial matters**. Many results from this survey impressed upon us the dominance of financial concerns for persons with developmental disabilities. Some concerns were related to quantity of assistance. For example, most consumers who had received services were satisfied with income assistance (e.g., SSI) and provision of medication. Yet a high proportion of consumers not receiving such services indicated a need for them. This finding suggests that, like case coordination services, consumers could greatly benefit from increased funding in these areas. Some services and supports related to financial matters were judged to be relatively unsatisfactory yet to show high levels of expressed needs among consumers. This was true for private health insurance, provision of medical equipment and supplies, and financial management assistance. This finding suggests the need to improve the quality of services or their delivery before expanding them through an infusion of dollars. The particular concerns of consumers with each of these services or supports is not clear. Additional research should be carried out to determine the exact nature of consumer concerns and to identify viable models for improved service delivery.

## Figure 9

## Summary on Satisfaction with and Needs for Life Supports and Services

| | Cause for Celebration | Good Quality Services But Need More | Cause for Concern |
|---|---|---|---|
| A. Case Coordination Services | | *Assessment/Plan Development<br>*Case Management<br>*Information & Referral | |
| B. Residential Services | *Housing Subsidy (e.g., Section 8)<br>*Architectural Modifications | *Homemaking Assistance or Training | |
| C. Educational Services | *Early Intervention<br>*Preschool Services | *Technical & Vocational Education | *Attendant/Aide<br>*Summer School & Related Programs |
| D. Health-Related | *General Medical Services<br>*Dental Services | *Provision of Medication | *Health Insurance (Private)<br>*Provision of Medical Equipment & Supplies |
| E. Transportation | | *To/From Work/School or Daily Activity<br>*To/From Non-Daily Activities<br>*For Leisure Time (Weekdays)<br>*For Leisure Time (Weekend) | |
| F. Individual Support Services | | | |
| 1. Respite Care | | | *In Home |
| 2. Mental Health & Behavioral Management | | *Mental Health/Counseling Services | |
| 3. Health-Related | | *Physical Therapy | *Occupational Therapy |
| 4. Human Resources | *Home Health Aides/ Visiting Nurses<br>*Attendant Care<br>*Homemaker/Chore Services | | *Companion/Friend/ Advocate Program |
| 5. Community-Related | | *Community Living Assistance & Training<br>*Self-Help/Support Groups | *Community Support Services |
| 6. Financial | | *Income Assistance (i.e., SSI) | *Financial Management Assistance |
| 7. Other | | *Adaptive Equipment/ Assistive Devices & Training | *Communication & Language Services |
| G. Caregiver Support Services | | | |
| 1. Respite Care | | | *In Home<br>*Out of Home |
| 2. Human Resources | | *Family Support Groups | |

**Personal independence**. Discussions with our interviewers as well as survey data have strongly impressed us with the relationship between independence and financial welfare in America. It would appear that today, a minimum level of income is essential for the sense of personal welfare and security that allows certain types of independence (e.g., choosing what to buy with spending money; choosing what to do on weekends) to take place. That many persons with developmental disabilities form a poor underclass is beyond doubt (see Chapter 7, Productivity). The types of services and supports that can contribute to financial welfare and security are detailed above. It is suggested here that provision of effective financial supports and services can also support personal independence. There are other data as well. One's ability to move around a community is also related to personal choice and independence. Our survey data indicated that transportation services were generally rated high by those receiving them but that unusually high levels of need remained among members of our sample. This finding suggests that, as with case coordination services, additional dollars should be used to reduce need for transportation among persons with developmental disabilities.

**Social and community integration**. Our data also suggest concerns over services and supports that contribute to social and community integration. These are the services and supports that allow consumers to participate in life in the

same ways and with the same people as persons without disabilities. The high expressed need for transportation services (reviewed above) is one reflection of that desire for participation. There are others. Some services and supports were rated as satisfactory (i.e., community living assistance or training; self-help/support groups; family support groups) by consumers involved in them but showing a high level of unfulfilled need within our sample. These services and supports should be supported and expanded to reach a wider population of persons with developmental disabilities. Other services and supports indicated a high level of need but low levels of satisfaction with current services (i.e., community support services; companion/friend/advocate program). Additional research should be carried out on programs offering these services to determine the particular reasons for consumer dissatisfaction and on models that promise to improve the effectiveness of these services and supports.

Of the four areas of emphasis presented in this summary, only case coordination services is directly concerned with effectiveness of the service system. Financial matters, personal independence, and social and community integration are all concerned with the quality of life of Virginia's consumers. This summary suggests some of the services and supports that can be improved or expanded to positively influence Virginians' quality of life. The next three chapters will present survey data to profile the quality of

life of persons with developmental disabilities in each of these dimensions: Chapter 5, Independence (i.e., personal independence); Chapter 6, Community Living and Integration (i.e., social and community integration); and Chapter 7, Productivity (i.e., financial matters).

## CHAPTER 5

## Independence

According to the Developmental Disabilities Assistance and Bill of Rights Act as amended in 1987, independence means " the extent to which persons with disabilities exert control and choice over their own lives". The key concept is to choose for oneself. Choice, of course, varies from setting to setting. Certain choices, appropriate with the context of ones own family, are inappropriate at work (e.g., choosing to wear shorts). Other choices might be appropriate for community but not for school (e.g., choosing one's associates). Choices, then, are related to settings. Conversely, an evaluation of the contribution of setting to a person's life should involve a consideration of choice, the independence allowed within a particular setting.

In considering independence, four settings will be evaluated separately. As mentioned before, there are better data for some settings than for others. These settings are: (a) living arrangements, (b) community, (c) education, and (d) work. Additional brief sections are concerned with other items measuring independence and correlates with independence.

### Independence and Living Arrangements

Certain decisions of choice involve the people and setting around which a person lives. For example, selection

of one's daily clothing is made at one's place of residence and will mirror one's level of dependence or independence. Four question in the survey were related to independence in living arrangements.

(a) Did you choose your attendant and/or residential support staff?

(b) Did you choose your roommate(s)/housemate(s)?

(c) Do you determine what clothes you wear?

(d) Do you usually decide how your personal space (home, apartment, bedroom, etc.) is decorated?

One type of question was concerned with social choices (i.e., selection of attendants or support staff; selection of roommates/housemates). Another type of question was concerned with personal preferences (i.e., selection of clothes; selection of room decorations). Table 39 gives the percentage of adults given choices in each of these areas.

**Table 39**

**Number and Percentage of Consumers with Choice on Two Domains Related to Independence in Living Arrangements: Adults**

| Domain/Choice | Yes, Unassisted | | Yes, With Assistance | | No | |
|---|---|---|---|---|---|---|
| Did You Choose....? | Number | Percent | Number | Percent | Number | Percent |
| A. Social | | | | | | |
| - Attendant or Residential Staff | 13 | 17.1 | 7 | 9.2 | 56 | 73.7 |
| - Roomates/Housemates | 15 | 19.7 | 10 | 13.2 | 51 | 67.1 |
| B. Personal Preference | | | | | | |
| - The Clothes You Wear | 94 | 66.2 | 35 | 24.6 | 13 | 9.2 |
| - How you decorate Your Personal Space | 83 | 59.3 | 32 | 22.9 | 25 | 17.8 |

In choices related to living arrangements, there is clearly a large difference between independence shown in social situations and independence displayed in personal preferences. Results indicate that most consumers responding to our survey were given no say whatsoever regarding the selection of attendant or residential staff or selection of persons who would be sharing rooms. Data indicated that degree of choice was related to the nature of the consumer's caregiver, however: caregivers with close relationships to consumers (e.g., relatives) allowed a greater degree of independence than did persons with more distant relationships (i.e., service workers).

In contrast , most consumers were given choices related to personal preferences. More than four of five and nine of ten consumers were given choices in decorating their personal space and choosing their new clothes, respectively.

**Independence in Community Settings**

Many decisions of choice go beyond the home to a larger community. Such choices as those involving friendships and leisure activities probably contribute significantly to life satisfaction. Seven questions from the survey related to this category are as follows:

(a) Do you usually choose what you do on weekends and evenings?

(b) Do you usually choose your friends and acquaintances?

(c) Do you give your own consent for medical care?

(d) Do you determine which agencies and organizations provide services and support to you?

(e) Do you go to the bank and deposit and withdraw money?

(f) Do you pay your own rent, gas/electric, and phone bills?

(g) Do you usually decide what things you buy with your spending money?

The first two questions were concerned with social and leisure choices while the second two questions were related to decisions regarding services. The final three questions were concerned with degree of independence in the handling of money. Results on independence within the community are given in Table 40.

Most adults with disabilities were involved in choices related to how their leisure time is spent (84.2%) and selection of their friends and acquaintances (87.9%).

Considerably fewer are currently involved in decisions about the services they receive. About seven of every ten consumers (70.9%) of respondents were involved in giving consent for medical care, and only 68.6% were given choices in which service agencies were to provide services and support to them.

Similarly, choices were limited in areas related to financial management and record keeping. Independent or assisted choice was allowed in the deposit and withdrawal of

**Table 40**

**Number and Percentage of Consumers with Choice in Three Domains Related to Independence in Their Communities: Adults**

| Domain/Choice | Yes, Unassisted | | Yes, With Assistance | | No | |
|---|---|---|---|---|---|---|
| Did You Choose....? | Number | Percent | Number | Percent | Number | Percent |
| A. Social and Leisure | | | | | | |
| - What You Do On Weekends/Evenings | 93 | 58.9 | 40 | 25.3 | 20 | 12.7 |
| - Friends and Acquaintances | 113 | 72.0 | 25 | 15.9 | 14 | 8.9 |
| B. Services | | | | | | |
| - Consent for Medical Care | 77 | 48.7 | 35 | 22.2 | 44 | 27.8 |
| - Service Agencies or Organizations | 49 | 31.2 | 43 | 27.4 | 60 | 38.2 |
| C. Personal Finances | | | | | | |
| - Go to the Bank to Deposit and Withdraw Money | 53 | 33.5 | 48 | 30.4 | 41 | 25.9 |
| - Pay Rent/Gas/Electric/Phone Bills | 51 | 32.5 | 36 | 22.9 | 49 | 31.2 |
| - What to Buy With Your Money | 101 | 64.3 | 35 | 22.3 | 19 | 12.1 |

money and the payment of personal bills in 63.9% and 55.4% of our respondents, respectively. Choice of things to buy with spending money was given either independently or with assistance in 64.3% and 22.3% of cases, respectively.

As with independence in living arrangements, independence within community was related to the nature of a person's primary caregiver. Generally, there was a progression from maximum to minimum independence with self as caregiver, family

or relatives as caregiver, friend or advocate as caregiver, and service worker as caregiver.

## Independence in Educational Settings

Independence versus dependence is a factor in virtually all of our experiences in life. It is an especially important consideration in settings we ourselves structure, but is also important in settings that are structured for us. In school, for example, the extent to which we are given the choice of what athletic activities to take part in, what topic to write a term paper on, and who to sit with over lunch certainly contribute to our sense of identity and independence.

With this understanding, it is unfortunate that the Consumer Satisfaction Survey failed to include any items that could be used to gauge the nature and level of independence in educational settings.

## Independence in Work Settings

As in structured educational settings, so with work settings, sense of independence contributes to both self-esteem and satisfaction. A considerable research literature now exists suggesting that autonomy in work is significant in contributing to the satisfaction many persons experience in work. For example, being able to choose and advance in jobs, being able to contribute to the work of a team, and being able

to socialize at work have all been found to contribute to worker's satisfaction with their jobs.

The current survey included only one item related to independence at work. That item was concerned with the degree to which persons with disabilities were able to choose their jobs or what they do on weekends. Due to the way the question was stated, it was not possible to separate choice in work from choice in weekend leisure activity. As with independence in educational settings, it is not possible to gauge the nature and independence in work settings or its contribution to life satisfaction.

Other Items Measuring Independence

Three other items related to independence were included on the survey. One items was concerned with independence in ownership, leasing or rental of house or apartment. Of respondents to our survey over the age of 20, 28.3% owned or independently leased or rented their home.

A second item was concerned with the degree to which respondents thought they were independent (i.e., How independent do you think you are?). Results are presented in Table 41. Better than four of each ten respondents indicated that they were somewhat (28.4%) or totally (13.4%) independent. While this finding is positive, it is important

**Table 41**

**Number and Percentage of Consumers Indicating Levels of Importance of Independence to Them: Adults**

| Question | Response | | | | | |
|---|---|---|---|---|---|---|
| | Very or Somewhat Important | | Neutral | | Somewhat Unimportant or Not Important At All | |
| | Number | Percent | Number | Percent | Number | Percent |
| How important is it to you to be independent? | 113 | 79.6 | 13 | 9.2 | 16 | 11.2 |

to add that 16.4% considered themselves to be somewhat dependent. About one in every seven consumers (14.9%) considered themselves "not at all independent". As with other items related to independence, the consumer's primary caregiver was related to perceived independence. Levels of perceived independence from high to low were associated with types of caregivers in the following order: self as caregiver, family or relative as caregiver, friend or advocate as caregiver, service worker as caregiver.

A third item was concerned with how important respondents believed independence was to their lives (i.e. How important is it to you to be independent?). Results are given in Table 42. To almost eight of every ten persons who responded to the survey, (79.6%) independence was very or somewhat important. But for one out of ten consumers (11.37%), independence was somewhat unimportant or not important at all. Comparing the results of this item to those of the previous one suggests that persons who have experienced

Table 42

**Number and Percentage of Consumers Indicating Levels of Perceived Independence for Themselves: Adults**

| Question | Response | | | | | |
|---|---|---|---|---|---|---|
| | Very or Somewhat Important | | Neutral | | Not Very or Not at All Independent | |
| | Number | Percent | Number | Percent | Number | Percent |
| How independent do you think you are? | 56 | 41.8 | 36 | 26.9 | 42 | 31.3 |

independence are those who value it most. In other words, independence is an acquired taste. Preference for independence is also related to primary caregiver. For example, persons who rated themselves as primary caregiver tended to experience a higher degree of independence and rate it as more important to them than other groups. In contrast, persons who designated a service worker as primary caregiver tended to have experienced a relatively low degree of independence and to rate it as less important to them than other groups.

## Correlates with Independence

Correlates with independence are important to policy analysis because they allow us to separate the conditions under which people tend to be dependent from conditions under which they tend to be independent. With such knowledge it is sometimes possible to change agency and state policy in ways

that maximally promote independence in the lives of persons with disabilities.

Current results have shed light on several factors that appear to be correlated with independence. These include race, personal or family membership in an advocacy group, and the relationship of the primary caregiver to the person with a disability.

**Race**. Among respondents to our sample, Blacks were involved in choices more often than were Whites. This trend appeared to be true for all settings and most questions for which data was available.

**Personal or family membership in an advocacy group**. For most questions related to independence, members of an advocacy group showed a higher percentage of persons making choices than for persons who were not members of an advocacy group. The same relationship appeared to be true for persons with disabilities whose family members were involved in an advocacy group, but the relationship did not appear to be as strong.

**Relationship with primary caregiver**. As noted above, several indices were found to be related to the nature of the consumer's primary caregiver. In all cases, persons who were their own primary caregiver showed the highest percentage of persons making choices, either with or without assistance, about their lives. The next highest percentage was usually found among persons whose primary caregiver was a relative. The third highest percentage was usually found among persons

whose primary caregiver was a friend or advocate, though occasionally, the elevation of percentages for relative and or advocate were reversed. In an overwhelming number of cases, the lowest level of independence was shown in the group of persons whose primary caregiver was listed as a service worker. These results for select questions related to independence are summarized in Table 43.

How can these results best be explained? One way is to suggest that the sequence of primary caregivers (i.e., self, relative, friend, service worker) actually reflects a progression of care for persons with increasingly severe disabilities. Statistical analysis does suggest that this is true to a degree. Nevertheless, those same analyses suggest that this does not account for the entire effect.

A second possible explanation is to consider that these four categories form a continuum based on closeness of relationship and hence, trust. That is, a person who is his or her own caregiver knows his or her needs and abilities best and, for that reason, would be expected to have a relatively high degree of confidence and trust in his or her decisions. If the primary caregiver were a family member, family knowledge of the person's needs and desires would tend to be lower with a lower lever of trust in the person's decisions. Similarly, friends and advocates have usually known the person with a disability less time than have his or her family members. Consequently, a lower lever of confidence and trust

Table 43

**Number and Percentage of Consumers Showing Independence* on Different Indices of Independence by Type of Primary Caregiver: Adults**

| Did you Choose | Primary Caregiver | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Self | | Parent/Spouse Other Relative | | Friend or Advocate | | Service Provider | |
| | Number | Percent | Number | Percent | Number | Percent | Number | Percent |
| Your Job | 33 | 89.2 | 38 | 65.5 | 8 | 47.1 | 7 | 24.1 |
| What You Do Weekends/Evenings | 37 | 97.4 | 50 | 86.2 | 15 | 88.2 | 19 | 65.5 |
| Give Consent for Medical Care | 36 | 94.7 | 42 | 72.4 | 12 | 70.6 | 15 | 51.7 |
| Clothes You Wear | 38 | 100.0 | 49 | 86.0 | 16 | 94.1 | 25 | 86.2 |
| Your Friends or Acquaintances | 37 | 97.4 | 50 | 87.7 | 15 | 88.2 | 25 | 86.2 |
| How Your Personal Space is Decorated | 36 | 94.7 | 44 | 77.2 | 12 | 70.6 | 23 | 79.3 |
| Go to Bank, Deposit and/or Withdraw Money | 34 | 89.5 | 32 | 55.2 | 11 | 64.7 | 13 | 44.8 |

* Data of this table reflect assisted and unassisted choice

would be expected in that person's independent decisionmaking. Fewer choices, and hence a lower level of independence would be expected. Finally, due to work loads and concerns related to liability, relationship closeness would be expected to be least between persons with disabilities and service workers. Less knowledge of the individual person would be expected as well as a lower level of caring about his or her welfare. Degree of trust in the person's independent behavior would be expected to be least. Least independence would be expected for these relationships.

This rationale, if correct, suggests that relationship closeness, with its differential levels of caring and knowledge of the individual, may be a significant contributor to the level of independence a person with a disability is granted. This hypothesis, if proven true, would have profound implications for the design of service systems interested in maximizing independence for persons with disabilities and for state policy.

An important qualification to the above statement should be made. The original design of this survey did not lend itself to a direct test of the hypotheses presented above. These represent inferences based on the best data this survey allowed. However, it was not possible to thoroughly test these hypotheses or to determine the degree of contribution to independence of the various factors noted above. The above should be considered only hypotheses until more thoroughly tested.

**Summary on Independence**

Survey results indicated that high levels of independence prevailed among consumers on certain life activities but low levels of independence on others. Generally, low levels of independence were found on tasks involving interaction with others in formal roles (e.g., selection of attendant care of residential staff). Low levels of independence were also found on tasks involving "the business of living" (e.g.,

depositing and withdrawing money from a bank). High levels of independence were found when choices involved personal preferences with little applicability to other persons or to one's welfare.

It might be said, then, that independence is both promoted and hindered in Virginia. Our data suggest that it is encouraged when a choice has little impact on the world at large. It appears to be hindered when a consumer's choice stands in conflict with that of a more powerful vested interest.

Exactly what does that mean for persons with developmental disabilities? Recent research into dependence has given credence to the importance of developing independent functioning in children and adults. Excessive dependence on others is said to be associated with impairment in occupational functioning and tendencies toward depression (American Psychiatric Association, 1980) and with self-depreciation, avoidance of adult activities, clinging social behaviors, delimited social networks, and perpetuation of dependent behavior patterns (Millon, 1981). The American Psychiatric Association has noted that "Chronic physical illness may predispose to the development of [excessive dependence] in children and adolescents" (p. 325).

Results and implications are clear. Current practices among many caregivers predispose consumers for whom they care to an adult life void of many adult roles and functions. We

are suggesting that lack of an adequate sense of independence leads many consumers to the periphery of adult life, a periphery from which it is virtually impossible to return.

## CHAPTER 6

## Community Living and Integration

Integration has been defined as "the use by persons with developmental disabilities of the same community resources that are used by and available to other citizens, and participation by persons with developmental disabilities in the same community activities in which non-disabled citizens participate together with regular contact with non-disabled citizens, and the residence by persons with developmental disabilities in homes or in home-like settings which are in proximity to community resources, together with regular contact with non-disabled citizens in their communities" (Developmental Disabilities Assistance and Bill of Rights Act as amended, 1987). The concept of integration incorporates both full participation and contact with persons without disabilities in various settings of one's community and the active participation in the same activities of a community that are available to persons without disabilities. It has, then, three aspects: (a) setting, (b) the nature of persons with whom one is socially involved, and (c) the tasks or activities in which a person with a disability is involved.

This section of the report on integration will be separated into sections by setting and will consider integration with persons and tasks within each setting. The

sections are as follows: (a) integration into family, (b) integration into community, (c) integration into educational settings, and (d) integration into work settings.

## Integration into Family

While the issue of one's family is not directly addressed by current Federal legislation, the phrases "in homes or in home-like settings" and "with regular contact with non-disabled (sic) citizens" does suggest that the nature of family may be an important variable in the equation that predicts how a person with a disability develops and the values that he or she takes into adulthood. Furthermore, both theory and empirical research strongly support the notion that a child's relationship to and experiences with parents and significant others is a dominant influence on his or her approach to the world. For example, evidence suggests that children whose parents remain relatively cold and emotionally distant grow up with a tendency not to engage others socially (Ainsworth, 1972; Bowlby, 1977). In a review of literature on culture and social support, Liu (1986) concluded that the degree of small group cohesion among persons with long-term psychiatric conditions was a significant predictor of psychological well-being. We should note that, for the purpose of this report, we are defining family as a small group of significant others with whom a consumer has a relatively close and enduring relationship.

This section will be divided into three parts: (a) the roles of child, parent, and spouse; (b) the relationship between family integration and other variables, and (c) the relationship between family integration and supports, services, and assistance needed.

**Roles of child, parent and spouse**. Limited information is available on the role of the child with a disability at home. Most of our sample of youth between birth and age 20 live in a single family home (87.5%) with other living arrangements occurring mostly at the upper end of this age spectrum (multi-family home, apartment, rooming house or residential hotel, 6.3%; congregate care facility or nursing home, 3.5%; institution, 2.8%). Only three of the children in our sample (2.2%) were not living with relatives. Analyses did suggest that at least 72.5% of our sample had siblings living with them at home though no direct measure of family structure was requested by the survey. Only 7.1% of our sample of children and youth had a personal services assistant. Most of these children (60.5%) lacked another person with a disability living at their same address though almost four of every ten respondents (39.6%) did have such a person living with them. Surrogates for 20.0% of children from birth to age 5 reported them feeling very lonely or remote from other people during the few weeks preceding the survey. That percentage increased to 53.3% for persons aged

6-20 years where it stabilized and then gradually diminished after about age 40.

The survey failed to collect information on the ways in which children with disabilities participated in the activities of their home settings. Despite the importance of measuring "quality of involvement," very little research or theory has dealt with this important domain in the development of children with disabilities.

The limited picture developed of a child with a disability is of a child living in a single-family home with one or more siblings without disabilities who commonly experiences fairly strong feelings of loneliness and remoteness from others. The incidence of those feelings increased in our sample with age. No information was available on the nature of family relationships or the nature of home life participation of children with disabilties.

Virtually no information was available from the survey on the roles of parent or spouse for persons with a disability. It should be noted, however, that 81.2% percent of adults with a disability over the age of 20 have never married. Significantly, of those who have married, 41.4% of marriages have terminated in divorce. The unusually low rate of marriage coupled with the high rate of divorce for those who do marry suggest the roles of parent and spouse for persons with a disability as a worthy area for future research.

**Relationship between family integration and other variables**. Analyses indicated several relationships between family integration for persons with disabilities and other dimensions of life. The ability to live in a single-family home was related to at least three dimensions of life: (a) life values, and (b) social activity and experience.

One area of influence related to family integration was in regards to life values. Over four of every five (85.5%) consumers with disabilities living in single-family homes indicated that community integration was very or somewhat important to them versus only 60.0% of persons living in settings where the integrity of a small group was not maintained (e.g., multi-family unit; institution). Likewise, 83.5% of persons living in single-family homes versus 56.0% of persons living in other settings responded with "very important" or "somewhat important" to the question: "How important is it to you to be productive?"

Why do such differences occur? One possibility is that life values are governed in part by the closeness of relationship that family integration promotes and that family integration also encourages a value of personal independence (see section on Independence). In other words, it is possible that the relationship closeness promoted in family settings (as opposed to the relationship distance of larger settings) supports a belief in self-worth that allows the person with

a disability to see himself or herself as a part of "real life", capable of being with and contributing to others, as opposed to requiring that others who are stronger provide help because of the disability. If such were true, we would expect a strong relationship between family integration and independence.

Data on closeness between primary caregiver and person with a disability and the life values of community integration, productivity, and independence are given in Table 44.

This table suggests that persons who have primary caregivers who know them well and who are emotionally close to them will tend to develop personal values inclining them toward independence, community integration, and personal productivity. The personal values of consumers who have primary caregivers who know them less well will tend to be less well defined in these areas. The relationship between primary caregiver and perceived independence, community integration, and productivitiy is even more striking (Table 45). Consumers with primary caregivers who know them well tend to see themselves as more independent, integrated and productive than persons with caregivers having more distant relationships.

These findings and others (see Chapter 5, Independence) strongly suggest that there exists a relationship between family integration and the development of values and

experiences related to independence, community integration and productivity. Additional research should be carried out to verify these findings. If the current findings are verified, there are profound implications for the ways in which service systems design programs and allocate resources.

**Table 44**

**Importance of Life Values to Consumers Having Different Types of Primary Caregiver: Adults**

| | Primary Caregiver | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Closeness in Relationship | | | | | | Distance in Relationship | |
| Life Value | Self | | Family/ Guardian | | Friend/Advocate Personal Care Attendent | | Service Provider | |
| | Number | Percent | Number | Percent | Number | Percent | Number | Percent |
| A. Independence | | | | | | | | |
| Very important or important | 38 | 100.0 | 44 | 81.5 | 13 | 81.3 | 20 | 80.0 |
| Not very important or not important | 0 | 0.0 | 10 | 18.5 | 3 | 18.7 | 5 | 20.0 |
| B. Integration | | | | | | | | |
| Very important or important | 34 | 94.4 | 48 | 88.9 | 13 | 86.7 | 20 | 80.0 |
| Not very important or not important | 2 | 5.6 | 6 | 11.1 | 2 | 13.3 | 5 | 20.0 |
| C. Productivity | | | | | | | | |
| Very important or important | 36 | 100.0 | 47 | 87.0 | 14 | 87.5 | 22 | 81.5 |
| Not very important or not important | 0 | 0.0 | 7 | 13.0 | 2 | 12.5 | 5 | 18.5 |

## Table 45

## Experiencing of Independence, Community Integration, and Productivity by Consumers with Different Types of Primary Caregiver: Adults

Primary Caregiver

Closeness in Relationship ——— Distance in Relationship

| Life Value | Self | | Family/ Guardian | | Friend/Advocate Personal Care Attendent | | Service Provider | |
|---|---|---|---|---|---|---|---|---|
| | Number | Percent | Number | Percent | Number | Percent | Number | Percent |
| A. How Independent do you think you are? | | | | | | | | |
| Totally or fairly Independent | 24 | 85.7 | 19 | 50.0 | 5 | 45.5 | 8 | 36.4 |
| Not very or not at all independent | 4 | 14.3 | 19 | 50.0 | 6 | 54.5 | 14 | 63.6 |
| B. How Integrated do you think you are? | | | | | | | | |
| Totally or fairly Integrated | 25 | 83.3 | 37 | 75.5 | 6 | 50.0 | 4 | 26.7 |
| Not very or not at all integrated | 5 | 16.7 | 12 | 24.5 | 6 | 50.0 | 11 | 73.3 |
| C. How Productive do you Think you are? | | | | | | | | |
| Totally or fairly productive | 22 | 78.6 | 31 | 63.3 | 9 | 64.3 | 12 | 48.0 |
| Not very or not at all productive | 6 | 21.4 | 18 | 36.7 | 5 | 35.7 | 13 | 52.0 |

A second area where family integration appears to be important is in the social sphere. For example, 75.0% of persons with disabilities living in single-family homes reported seeing friends without disabilities regularly versus only 70.0% of persons living in other settings (Table 46).

Table 46

**Number and Percentage of Consumers Who See Friends Without Disabilities Regularly: Consumers Living in Single Family Homes Versus Consumers Living in Multifamily and Institutional Settings**

| Consumers | Do you see non-disabled friends regularly? | | | |
|---|---|---|---|---|
| | Yes | | No | |
| | Number | Per-cent | Number | Per-cent |
| Living in Single-Family Homes | 54 | 75.0 | 18 | 25.0 |
| Living in Multi-Family or In-stitutional Settings | 56 | 70.0 | 24 | 30.0 |

Not only is contact more frequent for persons living in single-family homes, social contact appears to involve more variety. For persons living in single-family homes, only 11.3% failed to name any families living around them and 33.8% were able to name 5-10 families. The corresponding figures for persons in other settings were 53.3% and 12.0%, respectively (Table 47). Further, a majority of persons living in single-family homes reported visiting with nearby families (85.9%), while the figure for persons in other settings was considerably lower (46.7%; Table 48).

Table 47

**Number and Percentage of Consumers Able to Name Closest Families by Name: Consumers Living in Single-Family Homes Versus Consumers Living in Multifamily or Institutional Settings**

| Consumers | Of the ten families living closest to you, how many would you say you know by name? | | | | | |
|---|---|---|---|---|---|---|
| | 0 | | 1-4 | | 5-10 | |
| | Number | Percent | Number | Percent | Number | Percent |
| Living in a Single-Family Home | 8 | 11.6 | 29 | 42.0 | 32 | 46.4 |
| Living in a Multifamily or Institutional Setting | 31 | 40.8 | 29 | 36.8 | 17 | 22.4 |

Table 48

**Number and Percentage of Consumers Who Have Visited With Nearby Families: Consumers Living in Single-Family Homes Versus Consumers Living in Multifamily or Institutional Settings**

| Consumers | Of these ten families that live close to you, how many have you ever visited with...? | | | | | |
|---|---|---|---|---|---|---|
| | 0 | | 1-4 | | 5-10 | |
| | Number | Percent | Number | Percent | Number | Percent |
| Living in a Single-Family Home | 10 | 14.1 | 37 | 52.1 | 24 | 33.8 |
| Living in a Multifamily or Institutional Setting | 40 | 53.3 | 26 | 34.7 | 9 | 12.0 |

## Integration and Community Settings

This section will be divided into three parts: (a) involvement in community settings, (b) the nature of social involvement and (c) the nature of task involvement.

**Involvement in community settings**. Involvement in community settings involves at least two concepts for professionals interested in policy analysis. The obvious concept is concerned with the degree to which persons with disabilities are actually spending time in the myriad of settings available in a community. Since a person must be relatively stable within a community to know about and become involved in its activities, however, a second question becomes important: "Does a person stay long enough in a community to become involved in its activities?" While there was no direct measure of stability on the survey, respondents were asked "How many times have you changed addresses in the past five years?" This item may stand as a general measure of potential for involvement in community settings with persons moving few times being more stable and having a greater potential for community involvement than persons moving many times. Results indicate a relatively high degree of stability in our sample with 83.8% having moved fewer than three times in the last five years. This finding suggests that, in general, the potential for involvement in community settings is high for persons with developmental disabilities. Results indicated differences across disability groups, however. Table 49 suggests that, while almost nine of every ten consumers with cognitive disabilities have averaged over two years between moves, only about two-thirds of consumers with mental illness can make the same claim.

Table 49

**Percent of Consumers Moving Two or Fewer Times in the Past Five Years**

| Disabilty Category | Number of Consumers | Percent of Consumers |
|---|---|---|
| Cognitive | 116 | 88.6 |
| Physical | 56 | 83.6 |
| Sensory | 38 | 77.6 |
| Mental Illness | 13 | 68.0 |
| For All Disability Categories | 223 | 83.8 |

Stability for persons with physical and sensory disabilities fall between these extremes. These data suggest that the potential for community integration may not be as great for persons with mental illness as for other groups. Additional research should be carried out to further clarify this relationship, however.

Actual involvement in community settings is of two types. One type is concerned with "the weekly business of living" such as food shopping, banking, and participating in worship. A second type of involvement is concerned with use of leisure time and may involved such settings as sports facilities and motion picture theaters.

The survey considered several settings related to weekly business and asked questions related to frequency and satisfaction with frequency for each. Table 50 provides data on these settings.

Table 50

**Frequency and Satisfaction with Frequency of Visiting Select Community Settings Related to the "Business of Living"**

| Setting | Frequency | | | | | | Satisfaction with Frequency | |
|---|---|---|---|---|---|---|---|---|
| | Once a Week or More | | 1-3 Times Each Month | | Less Than Once A Month or Never | | Percent Wanting to Visit More Often | |
| | Number | Percent | Number | Percent | Number | Percent | Number | Percent |
| Supermarket/Food Store | 162 | 53.5 | 93 | 31.0 | 47 | 15.5 | 73 | 25.4 |
| Church or Synagogue | 137 | 45.2 | 47 | 15.5 | 113 | 37.3 | 91 | 32.0 |
| Shopping Center, Mall or Other Retail Store | 127 | 41.8 | 126 | 41.4 | 50 | 16.4 | 106 | 36.9 |
| Restaurant | 108 | 35.5 | 133 | 43.8 | 62 | 20.4 | 139 | 48.3 |
| Bank | 64 | 21.6 | 96 | 32.3 | 137 | 46.1 | 35 | 13.4 |
| Bars, Taverns | 14 | 4.8 | 11 | 3.7 | 270 | 91.5 | 28 | 12.3 |

Community involvement varies considerably across settings. For example, about 85% of consumers reported visiting a supermarket or food store one or more times a month. In contrast, only 54% reported visiting a bank one or more times monthly and only about 8% reported visiting bars or taverns each month. Satisfaction with the frequency of visiting these settings did not appear to be related to be frequency of current visiting. Rather, it appeared to be related to the potential for social contact and leisure in each setting. For example, while 48.3% and 36.9% of consumers wanted an increase in frequency of visiting restaurants and

shopping centers, respectively, only 25.4% and 13.4% wanted an increase in frequency of visiting supermarkets and banks, respectively. This pattern suggests that a strong desire for many persons with developmental disabilities may be to increase the time they spend in settings that allow increased social contact. This hypothesis is supported by data (Table 51) indicating that satisfaction with leisure is lower than satisfaction with any other major life domain for which comparable data were obtained.

There are additional data of interest when traditional leisure activities are considered (Table 51). Only about a fifth of consumers participate in each of the four most commonly used leisure settings ten or more times annually: motion pictures (25.5%); sporting events (21.6%); community or civic groups (19.9%); athletic facilities (17.7%). Two leisure activities (i.e., live popular music performance; live theater performance) show a very low level of participation and the highest level of desire for an increase in frequency of participation. All leisure pursuits for which data were requested show an unusually high percentage of consumers who are never involved in their associated community setting. For example, almost seven of ten consumers did not visit an athletic facility in the last year. Over a third failed to visit a movie theater and almost half did not attend a sporting event. These data suggest that there may exist considerable differences in the lives of consumers relative

**Table 51**

**Frequency and Satisfaction with Frequency of Visiting Select Community Settings Related to Leisure Interests**

| Setting | Frequency | | | | | | Satisfaction with Frequency | |
|---|---|---|---|---|---|---|---|---|
| | More Than 10 Times Yearly | | 1-5 Times Yearly | | Never | | Percent Wanting to Visit More Often | |
| | Number | Percent | Number | Percent | Number | Percent | Number | Percent |
| Motion Pictures | 77 | 25.5 | 114 | 37.7 | 111 | 36.8 | 111 | 39.8 |
| Sporting Events | 65 | 21.6 | 93 | 30.9 | 142 | 47.2 | 113 | 41.1 |
| Community or Civic Groups | 59 | 19.9 | 41 | 13.8 | 190 | 64.0 | 80 | 30.7 |
| YMCA/YWCA or Other Athletic | 53 | 17.7 | 36 | 12.0 | 207 | 69.2 | 112 | 42.0 |
| Live Popular Music Performance | 19 | 6.3 | 106 | 35.2 | 174 | 57.8 | 146 | 53.1 |
| Live Theater Performance | 12 | 4.0 | 118 | 39.2 | 168 | 55.8 | 146 | 50.0 |

to integration in leisure activities. While there appear to be a few who are integrated, leading lives similar to persons without disabilities, there are many who are isolated within the communities in which they live. There is a tendency for these persons to prefer more passive leisure activities (e.g., motion pictures; live theater performance) to more active ones (e.g., community groups; use of athletic facilities).

Nature of social involvement. A second important aspect of community integration is involved with the range and quality of social involvement in one's community. Social involvement may partly be determined by one's living arrangements. Is one's single-family home in a neighborhood

or a rural setting? Does one live in a setting that encourages non-family social contact (e.g., congregate care facility) or discourages it (e.g., single-family home)? Data on living arrangements for consumers over and under the age of 22 are presented in Table 52. These data suggest that, while the vast majority of youth live in single-family homes with members of their own families, that is not true for consumers over the age of 22. For our adult sample, there was considerable shift in living arrangements to multi-family homes, congregate care facilities, and institutions. While only 12.0% of youth lived in these types of facilities, fully 54.0% of adults were involved in such living arrangements. These data suggest the potential for greatly increased social contact in adulthood. Yet for social integration to be successful, social contact must be with both persons with and without disabilities. Based on this criterion, social integration for our sample has been a failure. Fully 60.7% of our respondents lived with one or more persons with a disability. That same percentage (60.0%) reported that they had no peers without disabilities living with them. It would seem that most persons with disabilities in our sample have the benefit of considerable social interaction with other persons with disabilities in their living settings but very little interaction with persons without disabilities. Yet segregation in living arrangements does not necessarily

indicate segregation within the community. Is it possible that visits and neighborhood contacts could make up for the

**Table 52**

**Frequency and Percent of Consumers Living in Various Living Arrangements: Consumers Above and Below the Age of 22**

| Living Arrangement | Less Than 22 Years Old | | More Than 22 Years Old | |
|---|---|---|---|---|
| | Number | Percent | Number | Percent |
| Home in a Neighborhood | 116 | 76.8 | 62 | 38.5 |
| Home in a Rural Area | 17 | 11.3 | 12 | 7.5 |
| Multifamily Home | 9 | 6.0 | 35 | 21.7 |
| Rooming House/ Aggregate Care Facility/Nursing Home | 5 | 3.3 | 36 | 22.4 |
| Institution | 4 | 2.7 | 16 | 9.9 |
| | 151 | | 161 | |

social limitations of one's living arrangements? In the case of our respondents, the answer is clearly "No!". When asked how many of the ten families living closest to them our adult consumers could name, over a quarter (26.3%) responded that they could name none at all. Sixty-three percent could name four or fewer. Thirty-three percent had never visited with or been visited by those same families. And 75.7% had visited with or been visited by fewer than half of those families. While non-family social contact in one's neighborhood is quite

limited for most consumers, contact through visiting friends and relatives is better. Over two-thirds (68.1%) of our adult consumers visited with friends or relatives once a week or more. Yet almost one of every five adult consumers (19.9%) were limited to visiting with close friends or relatives once a month or less. Over one-fourth (26.1%) answered the question "Do you have any friends/acquaintances who you see regularly who do not have a disability?" with "No". Absence of friends without disabilities was particularly notable for consumers with cognitive disabilities and mental illness. For these two groups especially, most friends of consumers tended to be other persons with disabilities.

**Nature of task involvement**. In addition to involvement in settings and with people, integration should also involve participation in the activities of a community. The concept differentiates passive from active involvement. Is a consumer who visits a bank as an observer integrated in the same sense as a person who uses the bank's services? Is watching a basketball game the same as playing? Is the person who is responsible for washing dishes in his or her home participating in the community of family in the same way as the person for whom this is done as a service? Unfortunately, questions of this survey failed to target this important area. Inferences drawn from the available data, however, suggest that for a significant proportion of consumers, participation

in the community activities of everyday living is a dream without reality.

## Integration In Educational Settings

Like community integration, consideration of integration in educational settings should involve at least three aspects: (a) involvement in educational settings, (b) the nature of social involvement, and (c) the nature of task involvement. Available data for each of these aspects will be reviewed below.

**Involvement in educational settings**. The concept of integration in educational settings is a complex one. It involves a continuum of settings. On one end of the continuum are educational services that are fully integrated, such as services provided in a regular classroom of a regular school. On the other end of the continuum are educational experiences that are fully segregated such as those provided at residential facilities. In between the ends of this continuum are services that are provided in partially integrated settings such as those provided in special classrooms of regular schools. These settings segregate children in classrooms but integrate those classes into the larger school environment. The philosophy of integration suggests that youth should be placed in as integrated a setting as possible while maintaining maximum possible academic and social learning. So how does Virginia fair in its attempts at

integration in education settings? Table 53 presents data on the three points of the continuum reviewed above. Of our sample of youth between the ages of 6 and 20, only 28.5%, about one in four consumers, reported being fully integrated in their educational settings. These youth attended school in a regular classroom of a regular school. About a fourth of this group had a supplementary resource room available. Almost half (46.7%) of persons between the ages of 6 and 20, attended school in partially integrated settings. These students reported placement in special classrooms with other

**Table 53**

**Number and Percentage of Current Students Experiencing Each of Three Degrees of Educational Integration**

| Degree of Integration/ Educational Setting | Number of Students | Percent of Students |
|---|---|---|
| A. Fully Integrated | | |
| Regular Class, Regular School | 22 | 21.0 |
| Regular Class, Resource Room | 8 | 7.5 |
| Total: Fully Integrated | 30 | 28.5 |
| B. Partially Integrated | | |
| Special Class, Regular School | 49 | 46.7 |
| Total: Partially Integrated | 49 | 46.7 |
| C. Segregated | | |
| Special School (Day) | 20 | 19.0 |
| Special School (Residential) | 6 | 5.8 |
| Total: Segregated | 26 | 24.8 |
| Total Students Aged 6-20 Years | 105 | 100.0 |

students with disabilities. The special classrooms, however, were in regular schools, allowing some opportunity for interaction with students without disabilities. The remainder of our youth, about a fourth (24.8%), attended school in fully-segregated facilities. These facilities included special day schools (19.0%) that allowed the student to return to his or her family after school hours, and residential facilities (5.8%) where students live away from their families on campus. Generally, this image of integration in Virginia's schools is not a positive one. It suggests that almost three-fourths of Virginia's youthful consumers experience some degree of segregation in their educational settings. Almost one-fourth are entirely segregated. But perhaps things used to be much worse. Is it possible that good progress has been made to bring integration in Virginia to where it now is?

While no direct measure of this question was possible with the current survey, available data suggest that this is not the case. Table 54 compares the levels of classroom integration for consumers currently aged 6-20 to those of the previous generation, consumers aged 21-40. There are striking differences.

In the previous generation, almost half (46.8%) of the consumers spent most of their educational time in fully integrated classrooms. Over a third (36.2%), however, spent most of their educational time in fully-segregated classrooms. A relatively small group (17.0%) attended special classes in

regular schools. For the current generation, educational settings are radically different. Almost half (46.7%) of our youth attended special classes in regular schools. There is a reduction over generations in the percent of consumers in fully-segregated educational settings (i.e., 36.2% to 24.8%). By far the greatest change is the reduction in the percent of consumers in fully-integrated educational settings over generations (i.e., 46.8% to 28.5%). These findings suggest

**Table 54**

**Frequency and Percent of Educational Settings for Two Cohorts: Current Settings for Consumers Aged 6-20 and Settings in which Most Time was Spent for Consumers Aged 21-40**

| Degree of Integration/ Educational Setting | Consumers Aged 21-40 (Old Generation) | | Consumers Aged 6-21 (Young Generation) | |
|---|---|---|---|---|
| | Number | Percent | Number | Percent |
| A. Fully Integrated (Regular Class in Regular School & Regular Class with Resource Room) | 44 | 46.8 | 30 | 28.5 |
| B. Partially Integrated (Special Class in Regular Schools) | 16 | 17.0 | 49 | 46.7 |
| C. Fully Segregated (Special Schools, Day or Residential) | 34 | 36.2 | 26 | 24.8 |

that, while significant change has occurred over the last two generations in the settings in which persons with developmental disabilities have been educated, not all change has been beneficial from the perspective of integration. On a positive note, there has been a significant reduction in the proportion of consumers educated in fully segregated settings. Concurrently, however, there has been a considerable reduction in the percentage of persons educated in fully integrated settings. The result has been a compromise of convenience, with the greatest proportion of consumers now educated in classes that are segregated within integrated schools.

**The nature of social involvement**. To be fully integrated within education means to have the same social experiences available that are available to persons without disabilities. The social environments and opportunities must not only be comparable, but interaction with persons without disabilities must be available as well. The current survey did not collect social information specific to educational settings. Nevertheless, given the finding that only about one-fourth (28.5%) of our consumers were involved in fully-integrated educational settings, it seems reasonable to infer that many consumers with developmental disabilities have social opportunities that are qualitatively different from those of persons without disabilities.

**The nature of task involvement**. Integration implies not only the same settings and social opportunities as persons

without disabilities, but also involvement in the same kinds of tasks within those settings as persons without disabilities. Unfortunately, the current survey did not collect information on the quality of involvement in various classroom settings.

## Integration In Work Settings

As important as the issues surrounding the role of work are to consumers, it is surprising that this survey offered so little insight on the quality and degree of integration into work settings. What data there were strongly suggested misunderstandings on the part of respondents as to the intent of questions. Additional insight on the degree and quality of integration into work environments of persons with developmental disabilities will have to await further research.

## Summary on Community Living and Integration

Community living and integration is, in its own right, as important as independence as a life value. Whereas independence denotes the ability to function apart from the skills and knowledge of other people, integration suggests the ability to be and function with others. The balance of personal independence and social integration has been a hallmark of our society from its beginnings and has been

essential to effective life roles in families, communities, schools, and at places of work.

From a societal point of view, effective social integration demands the openness of society's institutions to all persons and the understanding and acceptance of persons of the differences of other persons whether the differences are those of race, religion, ethnic background, or physical or mental capacity. From the perspective of this report, effective social integration suggests that the institutions of American society be open to including persons with developmental disabilities as valid participants in their endeavors. It also suggests that persons both with an without disabilities have the experiences that allow them to appreciate and value their differences to accept one another as people worthy of respect and capable of friendship and love. We suggest that the primary mechanism for such learning is simply the involvement of persons with and without disabilities together.

Out data suggest that such involvement does occur in families of origin with most families providing a warm and integrated environment in early life. Persons not integrated within families (e.g., persons living in multi-family units or institutions) show less variety in social contacts, lower personal commitment to the values of independence, social integration, and productivity, and less satisfaction with life.

Data suggest that barriers to social integration begin to develop when children begin to expand their base of experience beyond their families. A high proportion of children with developmental disabilities are isolated within their communities. Most social contact, even into adulthood, remains with family members. About 75% of children in school face some degree of segregation. About a fourth are entirely segregated, having no contact in school with peers without disabilities.

Given these childhood patterns, it is not surprising that adulthood for persons with developmental disabilities is characterized by high levels of isolation, the absence of traditional adult roles demanding social integration, and the prevalence of depression.

The exact cause of these disturbing findings is not clear. What is clear is that Virginia has thus far failed in its attempt to promote social integration for persons with developmental disabilities. The "F" on this report card is significant - for it is in a subject area that Virginia's children cannot repeat. For when a child learns an existence of social isolation in childhood, he or she invariably continues that pattern into adulthood.

## CHAPTER 7

## Productivity

The Developmental Disabilities Assistance and Bill of Rights Act of 1987 defines productivity as "engagement in income-producing work by a person with developmental disabilities which is measured through improvements in income level, employment status, or job advancement, or engagement by a person with developmental disabilities in work which contributes to a household or community." Productivity is defined, then, in two ways. First, it is defined as improvement in income level, employment status, or job advancement over time for persons who work. The legislation, however, also allows that persons who do not work for pay are productive when they contribute to a household or community. As with other constructs, productivity is related to setting. Adults may be productive relative to their living arrangements (i.e., "contribute to a household"), their community (i.e., "contribute to a ... community"), or their employment (i.e., "in income-producing work"). While it is not included in this definition, it should also be clear that both youth and adults can be productive in educational settings.

As with the consideration of independence and integration, four settings will be considered separately.

These settings are: (a) living arrangements, (b) community, (c) education, and (d) work.

**Productivity and Living Arrangements**

According to federal legislation, one way to be productive is by making contributions to one's living space or to the people who live within that space. One type of productive behavior is concerned with household tasks (e.g., parenting; counseling; discussion to resolve joint problems). Only two questions on this survey attempted to gain information of this type. One question asked "How many hours last week did you spend doing housework in your own home?" Of the 137 adults responding, 30 (21.9%) reported doing no housework at all. The hours for those doing housework ranged from 1 - 40 hours with the average person so engaged for 4.4 hours that week. Interestingly, a large percentage of persons responding indicated a need for homemaking assistance or training (Due to Survey design, it was not possible to differentiate those needing assistance from those needing training). This item, while less than ideal, does suggest either a need for additional homemaking services or, more hopefully, that with an increase in homemaking training, many persons with developmental disabilities might become more productive in this arena. Additional research is required to determine the extent of need, however.

A second question inquired as to the number of hours spent in helping family, friends, or neighbors in the week preceding the survey. Almost half of those responding (46.7%) spent no time assisting others. Those who did assist others spent on average of 6.2 hours in helping activities. The range of time spent was from one to 28 hours. Due to the way in which the Survey was constructed, it was not possible to determine whether the assistance given was within the context of a person's living arrangements or his or her community. Nevertheless, it is probably reasonable to assume that a sizable proportion of time given in assistance was provided in the person's home.

**Productivity in Community**

Productivity, as defined by law, may also involve making contributions to one's community. One type of community contribution is that of direct service, as in the case of providing assistance to peers or children. A second type of community contribution is concerned with membership and participation in groups of a community, such as civic groups. A third type of community productivity involves the more formal roles of citizenship, such as voting. Four questions of the Consumer Satisfaction Survey were concerned with productivity in community settings:

(a) How many hours last week did you spend helping family, friends, or neighbors?

(b) How many hours last month did you spend doing civic or community work or other volunteer work?

(c) Are you a member of a consumer/advocacy group such as the Association for Retarded Citizens, the National Head Injury Foundation, the National Alliance for the Mentally Ill, United Cerebral Palsy, the Epilepsy Foundation of America, People First, or any other group?

(d) Did you vote in the most recent general election?

Data on the item regarding direct service to peers and children was reviewed in the previous section of this report. Results indicated that over half of the consumers surveyed spent time in assisting others in the week prior to the survey, averaging 6.2 hours in this activity. It was not possible to separate time spent helping family (productivity within living arrangements) from time spent helping neighbors and friends (productivity within community). Nevertheless, it is probably reasonable to assume that many consumers with severe disabilities donate weekly time toward the assistance of others within their communities.

Data on productivity in a more formal capacity are also available. Only 25.7% of persons responding to the survey indicated participation in "civic or community work or other volunteer work" during the month prior to the survey. Time donated ranged from 0 to 98 hours with an average donation time per respondent of 3.6 hours. Comparing the time spent

in personal direct services to that spent in civic service is instructive. Respondents were over seven times more likely to serve in an informal, direct service capacity (e.g., assisting family or friends), than in a more formal, structured one. This finding suggests that the political and social influence of consumers may be reduced through a low level of participation in the traditional, organized mechanisms of community power (e.g., civic organizations that provide networks of influence; advocacy groups). The reader is reminded that only 27.6% of consumers were members of advocacy or consumer groups and only 3.0% of our sample characterized themselves as a part-time or full-time volunteers. Yet only 25.7% characterized themselves as either retired or unable to work. These results suggest that increased participation within community is certainly possible and that such an outcome is likely to increase community productivity.

Of adults responding to the survey, 39.3% voted in the last election. This figure is seen as surprisingly low for an interest group with a strong set of needs related to political mechanisms.

The survey did not lend itself to collection of information on the reasons for the relatively low level of community participation by consumers. This would appear to be a desirable focus for future research, particularly in the

light of current national and state trends promoting personal empowerment and political and social participation.

**Productivity in Educational Settings**

While federal legislation does not specifically include educational settings as ones related to productivity, we have chosen to describe the educational involvement of adults in this section. We will assume that education produces a product of significance to both society and person with developmental disabilities. Information on productivity for educational settings is, however, quite limited. We should also caution the reader that survey results suggest that respondents may have been responding at times to past experiences as well as current ones. Results given as current ones, then, should be viewed with caution and verified through other means.

Of our sample, 26.6% of adults were currently enrolled in educational settings. Of that number, 61.0% were enrolled in vocational or technical education, 8.4% in post-secondary education, 7.8% in literacy or basic education, 5.8% in summer school or related programs, and 1.3% in homebound education. This variety of educational involvement suggests that a broad segment of persons with educational needs (e.g., literacy versus post-secondary educational needs) use traditional educational mechanisms. It also suggests that less traditional educational structures are less commonly used

(e.g., homebound education). It is noteworthy that traditional supports for educational productivity are relatively infrequently used among members of our sample (i.e., after school tutor, 4.9% of persons in school; aide or attendant, 19.5% of persons in school).

Table 55 shows the satisfaction with services among adults currently receiving educational services. With the exception of homebound education, satisfaction with direct educational services are generally high, especially in educational settings with clear application to future life

**Table 55**

**Number and Percentage of Consumers Receiving Educational Services and Supports Indicating they were Satisfied or Very Satisfied with Services: Adults**

| Educational Services and Supports | Response | |
|---|---|---|
| | Satisfied or Very Satisfied | |
| | Number/Total | Percent |
| A. Services | | |
| Vocational/Technical Education | 25/28 | 89.3 |
| Literacy/Basic Education | 9/12 | 75.0 |
| Post-Secondary Education | 9/13 | 69.2 |
| Summer School & Related | 6/9 | 66.7 |
| Homebound Education | 3/8 | 37.5 |
| B. Supports | | |
| Aide or Attendent | 4/8 | 50.0 |
| After-School Tutor | 0/4 | 0.0 |

(e.g., vocational education; literacy). Satisfaction with educational supports (i.e., tutors, aides) are considerably lower, however. The low level of usage of educational supports coupled with the relatively low level of satisfaction with those supports among consumers currently receiving them suggest that this may be an important area for additional study.

Educational productivity may be limited by educational needs that are not met. From that perspective, it is noteworthy that a majority of adults with a developmental disability indicate that they have educational needs remaining. Survey results on educational needs are presented in Table 56. Clearly the largest groups are concerned about knowledge and skills related to employment (e.g., vocational/technical education, 59.1%; post-secondary education, 33.3%) though more than one in every four persons with a developmental disability indicate needs for adult literacy or basic education services as well. These latter services are those generally conceived as allowing persons to achieve a <u>minimum</u> standard (from an educational perspective) of performance in everyday activities. From the perspective of educational supports, one in four persons has a need for direct assistance by an aide or attendant. Considerably fewer (9.0%) indicated a need for a supplementary, after-school tutor. For most adults, educational supports did not include transportation. Almost nine of every ten (89.7%) of adult

Table 56

**Number and Percentage of Consumers Indicating Needs for Educational Services or Supports: Adults**

| Educational Service or Support | Slight, Moderate, Strong, Primary, or Urgent Need | |
|---|---|---|
| | Number/Total | Percent |
| A. Services | | |
| Vocational/Technical Education | 55/93 | 59.1 |
| Post-Secondary Education | 24/72 | 33.3 |
| Adult Literacy/ Basic Education | 20/72 | 27.8 |
| Summer School & Related | 12/67 | 17.9 |
| B. Supports | | |
| Aide and Attendent Services | 18/72 | 25.0 |
| After-School Tutor | 6/67 | 9.0 |

respondents agreed with the statement: "Getting to and from school is convenient".

Finally, limited information was available on why educational services were not being received by persons with developmental disabilities. Of the list of reasons for not receiving services provided on the survey, by far the most common selection by respondents was "any other reason". This means that the investigators do not know why the majority of the respondents do not receive needed services. Of those marking other items, similar patterns of response occurred across educational needs. The most frequent need marked was "not eligible by type or degree of disability". Other commonly marked items included "service is too expensive to

obtain", and "service is not available in the area". These three responses, taken together, suggest the possibility of service system problems related to (a) provision of services based on type of disability rather than functional need, leading to inequity of service across disability groups, (b) costs above the means of persons with disabilities to pay, and (c) inequitable distribution of service resources geographically.

## Productivity in Work Settings

The most widely used definition of productivity refers, without a doubt, to work settings. The traditional means of "producing" in America is through paid employment. The federal definition of productivity, as reviewed above, gives a new twist to the term, however. Rather than referring to merely producing via paid employment, the definition includes an additional feature. According to federal legislation, productivity as it pertains to paid employment refers to "improvements in income level, employment status, or job advancement" (emphasis added). Thus, productivity incorporates the concept of improvement over time in both the quantity and quality of paid employment for persons with developmental disabilities.

Below we will first profile the current workforce represented in our sample. We will then deal with the more difficult measures involving change over time.

Current employment data. Results for this survey indicate that just over half (52.4%) of our sample of adults over the age of 22 were available for work. Of those available for work, 61.8% were working full-time and 23.7% were working part-time. 7.9% were unemployed but looking for work while 7.1% were serving as part- or full-time volunteers. Persons not available for work were characterized by several conditions: full-time student (22.8%); unable to work (20.7%); retired (4.1%). The findings are presented in tabular form in Table 57.

Table 57

**Status for Consumers Available for Work, Consumers Unavailable for Work, and Total Sample: Adults**

| Status | Available for Work | | Total Sample |
|---|---|---|---|
| | Number | Percent | Percent |
| A. Available for Work | | | |
| Work Full-Time | 47 | 61.8 | 32.5 |
| Work Part-Time | 18 | 23.7 | 12.4 |
| Unemployed, Looking for Work | 6 | 7.9 | 4.1 |
| Part/Full-Time Volunteers | 5 | 6.6 | 3.4 |
| B. Unavailable for Work | | | |
| Full-Time Student | 33 | 47.8 | 22.8 |
| Unable to Work | 30 | 43.5 | 20.7 |
| Retired | 6 | 8.7 | 4.1 |
| Total Sample Size | 145 | | |

Data are also available on current wage scales for persons employed full- and part-time. Persons characterizing themselves as working full time earned an average of $6.35 per hour and worked for an average of 37.0 hours in the week prior to the survey. At that rate, the annual salary for full time workers with disabilities would be $12,216.36. In contrast, persons working part-time averaged only $4.14 hourly and worked an average of 21.1 hours per week (annual salary equivalent of $4,368.00). Working full-time students averaged $106.50 per week in a work week averaging 24.7 hours (average hourly wage, $4.31).

Data were also available on the nature of jobs held by persons with disabilities. Currently, the largest occupational grouping for persons with developmental disabilities is that concerned with operatives and laborers. This category of job is traditionally considered to be the category with least occupational status and requiring the least education and experience credentials for entry. Almost half (46.0%) of our employed sample worked in operative or labor-related jobs. About a fifth (19.0%) of our employed sample worked in jobs one step up the occupational status ladder, in jobs as service workers, craft workers, or in agriculture, forestry or fishing. The smallest occupational grouping for persons with developmental disabilities was for sales and clerical workers (14.3%). Finally, one in five persons (20.7%) worked in a professional-level occupation, as

a teacher, librarian, counselor, manager or official or in a job requiring highly technical expertise. This class of jobs mirror the highest level of occupational status.

**Change in employment over time**. As reviewed above, the federal definition of productivity currently in use defines productivity as improvement over time in one of three arenas related to paid employment: (1) income level, (b) employment status and (c) job advancement. Of the three measures, the survey provides direct measures of changes in income level and of employment status for a small sample of adults. The measure of job advancement is less direct and requires more interpretation. Each measure of change in productivity is reviewed below.

Change in income level was measured by a comparison of current weekly income to weekly income reported from the respondent's most recent previous employment. Table 58 presents data from this comparison. Clearly, whether one finds an increase in productivity among persons with disabilities depends on the measure chosen. For persons working full time, a significant decrease in hours worked (53.4 to 37.0 hours) is coupled with a considerable increase in hourly wage ($3.32 to $6.35 per hour). The net result is an increase of almost a third in weekly income ($177.47 to $234.93). This results in an increase in projected annual salary form $9,228.44 to $12,216.36. Clearly, if these results are to be trusted, there was a significant increase

in income from last previous job to the current one. Nevertheless, it should be noted that only the current job is reported as full time. It is possible that several of the previous jobs reported by consumers had been part-time, causing a spuriously low weekly wage figure (the weekly average hours of 53.4 would argue against this interpretation, however).

With persons working part-time, results are quite different. While the average hours worked weekly dropped in half (44.7 to 21.2), the hourly wage increased across jobs only slightly ($3.48 to $4.14). This resulted in a

**Table 58**

**Productivity as Measured by Change in Income Level - Weekly Income for Most Recent Previous Job Compared to Weekly Income For Current Job: Adults**

| Employment Classification | Most Recent Previous Job | Current Job |
|---|---|---|
| A. Full Time | | |
| Average Hours Per Week | 53.40 | 37.00 |
| Average Pay Per Hour | $ 3.32 | $ 6.35 |
| Average Pay Per Week | 177.47 | 234.93 |
| Projected Annual Salary (Avg. Pay/Week x 52) | 9,228.44 | 12,216.36 |
| B. Part Time | | |
| Average Hours Per Week | 44.70 | 21.20 |
| Average Pay Per Hour | $ 3.48 | $ 4.14 |
| Average Pay Per Week | 155.67 | 87.40 |
| Projected Annual Salary (Avg. Pay/Week x 52) | 8,094.84 | 4,544.80 |

considerable reduction in weekly wage, from $155.67 to $87.40 per week. The annual projections for these weekly wages are $8,094.84 (past job) and $4,544.80 (current job). As with full time employment, we are assured only that the current job is part-time. It is quite possible that some consumers' previous jobs were full time. This interpretation is supported by the finding that persons appearing in the part-time column worked an average of 44.7 hours weekly in their previous job. Perhaps the most equitable solution for measuring productivity by comparing previous and current income levels is to combine the full- and part-time categories. Results of this procedure are presented in Table 59. These figures reflect a 13.2% gain in income between most recent previous and current employment. Using this short-term and highly market-sensitive measure as our sole index of income-related productivity, we may say that productivity for persons in our sample showed a moderate increase across jobs.

**Table 59**

**Average Weekly Wage and Projected Annual Salary for Most Recent Past Job and Current Job: Adult**

| | Most Recent Past Job | Current Job |
|---|---|---|
| Average Weekly Wage | $ 171.43 | $ 194.08 |
| Projected Annual Salary | 8,914.36 | 10,092.16 |

Another measure of change in employment over time is employment status, the proportion of persons available for work who are actually employed. Survey results indicated that 76 of 145 adult respondents (52.4%) were available for work at the time of the survey. Of that number, 65 (85.5%) were employed. While this finding appears generally favorable, there is one qualifier that may temper our enthusiasm. First, a very large percentage of adult consumers gave responses indicating a lack of availability for work (47.6%). Past experience suggests that many persons drop out of the job market due to frustration after fruitless efforts at seeking employment. These persons often choose alternative lifestyles (e.g., student role; retiree role) rather than continuing to fail at job seeking. Many of these persons would accept a job if offered but are involved in other activities.

Measures of job advancement are less direct. One way of considering job advancement would be to compare the occupational status of a person's current job with his or her most recent past one. Using such a method, jobs of our sample as a whole could be coded to see if there were shifts in the relative status or prestige of past and current occupations. Such an analysis was conducted. Results are presented in Table 60. The table includes four classes of occupation ranked in order by occupational status or prestige. The highest level of prestige (i.e., professional and technical

**Table 60**

**Productivity as Measured by Changes in Occupational and Employment Status Over Time: Adults**

| Employment Classification | Occupational Status | Most Recent Previous Job | | Current Job | |
|---|---|---|---|---|---|
| | | Number | Percent | Number | Percent |
| A. Professional and Technical (e.g., teachers; counselors; managers) | High | 11 | 20.0 | 13 | 20.7 |
| B. Sales and Clerical (e.g., salesperson; secretary) | Medium-High | 12 | 21.8 | 9 | 14.3 |
| C. Craft, Service, Agriculture, Forestry Fishing Workers (e.g., painter; TV repair person) | Medium-Low | 21 | 38.2 | 12 | 19.0 |
| D. Operatives and Laborers (e.g., painter's helper; machine operator) | Low | 11 | 20.0 | 29 | 46.0 |

occupations) showed very little change over time with about 20% of adult working consumers working in this type of occupation both currently and in the recent past. There was a difference in the next most prestigious category of occupation, however. Currently, sales and clerical workers make up 14.3% of our adult consumer workforce. When we consider the jobs held just prior to current positions, however, 21.8% of adult consumers held clerical or sales positions. This reduction in proportion of jobs in this category of occupation cannot indicate advancement since percent of jobs at the next higher level remained about the same. The reduced percentage of jobs in this category probably meant a demotion in occupational status or prestige. Consumers who had worked as sales or clerical workers are likely to have taken jobs of lower occupational status.

Likewise, the next lowest category of occupations (i.e., service and craft workers, and workers in agriculture, forestry and fishing) also showed a reduction in percent of jobs from recent past to the present, suggesting a diminishing of status and prestige. These two findings suggest the likelihood of the opposite of advancement for these classes of occupation. They appear to reflect a demotion in status and prestige if not in salary. The lowest level of occupational status and prestige, operative and labor occupations, showed the greatest gain in percent of jobs from recent past to the present time. While only 20% of consumers held this class of occupation just prior to their current job, almost half (46.0%) held such a job at the time of the survey. Unlike data on change in income, these data suggest that productivity, as defined by federal regulations have shown a significant decrease for persons with developmental disabilities.

**Summary of Productivity**

Intuitively, it seems to us that accomplishment through productivity is a major factor in the establishment of adult identify. Productivity occurs through the balance of independence and social integration that allows individuals to "pay back" society by performing activities acknowledged to be of value by other persons. Productivity may be rewarded directly through payment of money (i.e., work for pay) or

through the expressed esteem of others (e.g., work as a hospital volunteer; cleaning house). In either case, it engenders a sense of self-worth through a contribution approved of by society. Some have said that productivity is the very reason for the importance of balance between independence and social integration. Whether the reason or not, productivity is clearly essential to the fulfillment of adult life.

The etiology in early life of a productive life orientation and the importance of society's role of encouragement is perhaps best reflected in a quote by Erik Erikson in discussing childhood.

> "The child's danger, at this stage, lies in a sense of inadequacy and inferiority. If he despairs of his...skills or his status..., he may be discouraged...and considers himself doomed to mediocrity or inadequacy. It is at this point that wider society becomes significant in its ways of admitting the child to an understanding of meaningful roles in its technology and economy. Many a child's development is disrupted when family life has failed to prepare him for school life, or when school life fails to sustain the promise of earlier stages." (Erickson, 1950, p. 260)

As reviewed in the previous chapters of this report, many children with developmental disabilities enter adult life with inadequate preparation. Inadequate preparation appears common in a number of domains related to adulthood including social and educational ones.

Inadequate preparation, when coupled with the closed nature of many work institutions, provides a sobering image of the typical consumer who would like to work. Of consumers

in our sample available for work, only 61% were working full time. The projected average annual income for a person with a developmental disability who worked full time was less than $13,000 a year. Most consumers worked in low-status, dead-end jobs.

In the chapter on independence, we suggested that experiences early in life predispose a child to a life of relative dependence or independence in adulthood. In the following chapter on living arrangements and community integration, we suggested that early life patterns characterized by social isolation and segregation also increased the likelihood of such patterns in adulthood. At the risk of being repetitive, we wish to draw the same conclusion here. We believe that poor social and educational preparation in childhood has a profound impact on employability as an adult. Furthermore, we suggest that certain orientations of childhood common to persons with developmental disabilities (e.g., dependence; social isolation), once learned, are unusually difficult to give up as an adult. Thus, both personal orientation and knowledge and skill deficits may serve as significant barriers to productivity.

We do not wish to de-emphasize the importance of societal, institutional and personal constraints. Barriers such as inaccessible buildings, limited or inappropriate accommodation, or prejudice are quite real and punishing to

their victims. Changes do need to be made. But such constraints were not considered by this survey.

From the perspective of the data accessible to us, two points should be emphasized. First, many adult consumers currently require a host of services and supports in order to work. We should commit ourselves to enhanced quality of life through meeting these needs. Second, if we wish to truly change the quality of life for future generations of persons with developmental disabilities, we must begin with our children today.

## CHAPTER 8

## Conclusions

As writers of this report, we must acknowledge that we did not know the extent of shadow facing persons with developmental disabilities. If you do not have a developmental disability, you probably did not know either. We still don't. We don't face the day-to-day demands of living within a society turned cold. Yet through this survey and report a small window of vision has been opened. We can begin to see and understand what it means to have a developmental disability.

Relative to persons without a disability,

- most persons with a developmental disability are alone,
- they are poor,
- they are uninvolved, standing on the periphery of life,
- they are told what to do,
- they are unproductive, and
- they are treated without respect and dignity.

Each Virginian with whom we have spoken has a different reaction to these facts. Some are angry. Others are sad. Many feel helpless and others frustrated. Some deny the existence of these Virginians and their plight. For this last group, it is our hope that you will never be able to deny again after reading this report. For all, we wish the

understanding that we should help, the confidence that we can help.

For it is our fervent belief that lives of shadow can be transformed, not in the twinkling of an eye, but with the dedicated work of many minds, hearts, and hands. There is job enough for all. Let us continue.

One of the authors has a wife who once taught in Florida. She was a gifted teacher and taught her students with love and compassion. Of all the accolades she received over the years, one became very special. It was written by a student whose life was generally not a pleasant one and who wanted to write her goodbye rather than say it. The note read, "You brung the sunshine into my rainy alleys. Thank you."

There are many ways to bring sunshine into the shadow of peoples' lives. A touch. A word of comfort. Working with an advocacy group. Planning. Deciding on legislation. Many other ways. Let each of us once again dedicate ourselves with renewed energy and commitment to bring sunshine into the rainy alleys of this life. Let that be our dream.

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INDEX


| | Pages |
|---|---|
| Acquiring New Skills (functional limitation) | 4, 26, 29, 34-37, 56, 58. |
| Adaptive Equipment/ Assistive Devices and Training | 76, 80, 86, 89, 106. |
| Adolescent Roles | xi, 11, 38, 41, 42-45, 46, 47, 49, 57. |
| Adult Day Services, Developmental | 71. |
| Adult Day Services, Non-Developmental | 71. |
| Adult Literacy | 43, 46, 57, 68, 70, 156, 157, 159. |
| Advocacy Groups | (see "Self-help or Support Groups"). |
| After-School Tutor | vii, 42, 45, 57, 67, 68, 69, 70, 157, 158, 159. |
| Aid to Families with Dependent Children | 100, 102. |
| Architectural Modification | 66, 106. |
| Assessment/Plan Development | (see "Case Coordination Services"). |
| Assisting Others | 153, 154. |
| Assistive Devices | (see "Adaptive Equipment/ Assistive Devices and Training"). |
| Attendant | (see "Onsite Attendant"). |
| Autism | 21, 22, 23, 24. |

Banking Activities . . . . . 136, 137.

Bars, Taverns, Visits to . . . . . 137.

Behavioral Problems . . . . . 23, 24.

Behavior Management Assistance and Training . . . . . 78, 80, 82, 91, 92, 95.

Blindness and Severe Visual Impairment . . . . . iv, 21, 23, 24, 25, 26.

Board for Rights of the Disabled . . . . . i, iv, 4, 5, 14, 16.

Caregiver Supports . . . . . 60, 90-102, 106.

Case Coordination Services . . . . . 60, 61-62, 104-105, 106.

Case Management Services . . . . . (see "Case Coordination Services").

Cerebral Palsy . . . . . iv, 21, 23, 24, 25, 26.

Change in Employment Over Time . . . . . 163-168.

Children's Specialty Services . . . . . 100, 102.

Child Role . . . . . xi, xii, 10, 11, 18, 37, 38, 39, 56, 58, 169.

Chore Services . . . . . (see "Homemaker/ Chore Services").

Church or Synagogue, Visits to . . . . . 136, 137.

Citizen Role . . . . . 18, 28, 38, 53-54, 56, 58.

Civic or Community Work Activities . . . . . 154.

Cognitive Disability . . . . . iv, viii, 21, 22, 27, 28, 29, 30, 31, 32, 33, 34, 36, 56, 60, 73, 81, 82, 83, 85, 86, 87, 88, 89, 90, 92, 94, 95, 96, 98, 99, 135, 136.

College (Post-Secondary Education) . . . . . 44, 46, 57, 68, 70, 156, 157, 158, 159.

Communicating (functional limitation) . . . . . 4, 19, 26, 27-28, 29, 35-37, 56, 58.

Communication and Language Services . . . . . 79, 80, 86, 88, 106.

Community and Civic Groups, Participation with . . . . . 49, 50, 138, 139.

Community Integration . . . . . iv, v, vi, xii, 2, 4, 5, 6, 7, 8, 9, 10, 11, 39, 102, 107, 108, 109, 125-150.

Community Living . . . . . (see "Community Integration").

Community Living Assistance or Training . . . . . v, 79, 80, 85, 86, 106, 108.

Community Mental Health Services . . . . . 100, 102.

Community Services Assistance Center . . . . . ii, iv, 5, 6

Community Settings . . . . . 112-115 (independence in); 134-143 (integration in); 153-156 (productivity in).

Community Support Services . . . . . v, 79, 80, 85, 86, 106, 108.

Competitive Employment . . . . . 71.

Companion/Friend-Advocate Programs . . . . . 79, 80, 83-84, 106, 108.

Consumer Empowerment Project . . . . . 4, 17.

Cooking/Meals-on-Wheels . . . . . 79, 80, 86, 89.

Cystic Fibrosis . . . . . 21.

Day Care (Adult) . . . . . 91, 92-93.

Day Care (Child) . . . . . 91, 92-93.

Day Treatment . . . . . 71.

Deaf and Hard of Hearing, Dept. of . . . . . 25.

Deafness and Severe Hearing Impairment . . . . . 21, 23, 24, 25

Demographic Characteristics of Sample . . . . . 4, 7.

Dental Services . . . . . 74, 75, 106.

Dependence . . . . . (see "Independence").

Depressive Illness . . . . . 21.

Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987. . . . . 1, 110, 125, 151.

Down's Syndrome . . . . . 21.

Early Intervention Services . . . . . 68, 70, 106.

Earning Income (functional limitation) . . . . . 4, 26, 33-37, 55, 58.

Education . . . . . 6, 7, 9, 60, 66-70, 96-98, 100, 106.

Education, Dept. of . . . . . 101.

Educational Settings . . . . . 115 (independence in); 143-148 (integration in); 156-160 (productivity in).

Eligibility for Participation in Survey . . . . . 4, 7, 15.

Emergency Health Services . . . . . 74.

Emotional Disability . . . . . 21, 23, 24, 26.

Employment . . . . . 6, 7, 8, 9.

Employment Data, for Sample, Current . . . . . 161, 163.

Employment Services . . . . . 72, 73.

Epilepsy . . . . . 6, 23, 24, 25.

Evaluation of the Service System . . . . . 7, 9.

Family . . . . . (see "Living Arrangements").

Family Care . . . . . (see "Housing").

Family Cash Assistance . . . . . 91, 92, 98, 99.

Family Counseling . . . . . 91, 92, 95, 96.

Family Education . . . . . 91, 92, 96, 97.

Family Support Groups . . . . . 91, 92, 93-95, 106, 108.

Financial Management Assistance . . . . . vi, vii, 79, 80, 86, 87, 105, 106.

Financial Welfare . . . . . vi, 86-87, 105.

Food Assistance/Food Stamps . . . . . vi, 79, 80, 86, 87.

Food Shopping . . . . . 136, 137.

Food Stamps . . . . . (see "Food Assistance/Food Stamps").

Friend-Advocate Program . . . . . see "Companion/ Friend-Advocate Program").

Functional Limitations . . . . . 26-37.

Gender (Sex) . . . . . 4, 19, 20.

General Health (Medical) Services . . . . . 74, 75, 106.

General/Specific Hospitals . . . . . 74.

Genetic Screening and/or Counseling . . . . . 74, 91, 92, 98.

Group Homes . . . . . (see "Housing").

Habilitation . . . . . 73.

Head Injury . . . . . 23, 24.

Health . . . . . 6, 7, 9, 60, 74-75, 82, 106.

Health Insurance (private) . . . . . vi, 74, 75, 105, 106.

Hearing and Visual Impairment . . . . . 21, 23, 24.

Homebound Education . . . . . 67, 68, 156, 157.

Home Health Aide/ Visiting Nurse . . . . . 79, 80, 83, 106.

Homemaker Assistance or Training . . . . . 64, 65, 106, 152.

Homemaker Role . . . . . 10, 11, 18, 28, 38, 54, 56, 58.

Homemaker/Chore Services . . . . . 79, 80, 83, 91, 92, 93-94, 106.

Housework . . . . . 152.

Housing . . . . . 6, 7, 8, 9, 60, 63-66, 127, 128, 139, 140.

Housing and Urban Development, Dept. of, Section 8 Rent Certificate . . . . . 100, 102.

Housing Subsidies (e.g., Section 8) . . . . . 65, 66, 106.

Income Assistance (i.e., SSI) . . . . . vi, vii, 79, 80, 86, 105, 106.

Independence . . . . . iv, v, vi, x, xi, 2, 4, 7, 8, 9, 10, 11, 33, 39, 64, 102, 107, 108, 109, 110-124, 130, 131, 132, 151, 170.

Independent Living Centers . . . . . 100, 102.

Individual Supports . . . . . 60, 78-90, 106.

Information and Referral . . . . . (see "Case Coordination Services").

Institution . . . . . (see "Housing").

Integrated . . . . . (see "Community Integration").

Integration into Community . . . . . (see "Community Integration").

Job Placement . . . . . 71, 72.

Learning . . . . . (see "Acquiring New Skills-functional limitations).

Legal Services . . . . . (see "Protective/ Legal Services").

Leisure Person Role . . . . . xii, 10, 11, 18, 37, 38, 47-52, 56, 58, 59, 76, 77, 112, 113.

Life Management (functional limitation) . . . . . 4, 26, 31-32, 34-37, 56, 58.

Life Roles . . . . . 8, 11, 18-59.

Living Arrangements . . . . . 110-112, 126-134, 141, 152-153.

Living on One's Own (functional limitation) . . . . . 4, 26, 32-33, 34-37, 55, 58.

Marriage . . . . . (see "Spouse Role").

Maternal and Child Health . . . . . 100, 102.

Meals-on-Wheels (functional limitation) . . . . . (see "Cooking/ Meals-on-Wheels").

Medicaid . . . . . 74.

Medical Assistance Services (Medicaid), Dept. of . . . . . 100, 101, 102.

Medical Equipment . . . . . (see "Payment/ Provision of Medical Equipment").

Medication . . . . . (see "Payment/ for Medication").

Mental Health Counseling . . . . . 79, 80, 81, 106.

Mental Health, Mental Retardation and Substance Abuse Services, Dept. of . . . . . i, ii, 25, 100, 101, 102.

Mental Illness . . . . . iv, viii, 21, 22, 23, 25, 27, 28, 29, 30, 31, 32, 34, 36, 37, 56, 60, 73, 81,82, 84, 85, 87, 92, 93, 94, 95, 96, 97, 135, 136.

Mental Retardation . . . . . iv, 6, 21, 23, 24, 25.

Mobility . . . . . (see "Moving from Place to Place-functional limitation").

Movies, Attendance at . . . . . 48, 50, 51, 138, 139.

Moving from Place to Place . . . . . 4, 19, 26, 30-31, 34-37, 56, 58.

Multiple Sclerosis . . . . . 21.

Muscular Dystrophy . . . . . 21, 23, 24.

Music (Live), Attendance at . . . . . 48, 50, 139.

National Association of Developmental Disability Councils (NAADC) . . . . . iv, 2.

Nursing Home . . . . . (see "Housing").

Occupational Therapy . . . . . 79, 80, 82, 106.

Onsite Attendant . . . . . vi, vii, viii, 42, 45, 57, 68, 69, 70, 71, 72, 73, 79, 80, 83, 106, 157, 158, 159.

Onsite Work Modification . . . . . 71, 72, 73.

Orthopedic Impairment . . . . . 21, 23, 24, 25.

Parent Role . . . . . x, xii, 10, 11, 18, 38, 47, 49, 54, 56, 58, 59.

Parent Training . . . . . 91, 92, 96, 97.

Partial Hospitalization . . . . . 71.

Payment for Medication . . . . . vi, 74, 75, 105, 106.

Payment/Provision of Medical Equipment . . . . . vi, 74, 75, 105, 106.

Pensioner Role . . . . . (see "Retiree Role").

Personal Care Attendant . . . . . (see "Onsite Attendant).

Personal Preferences . . . . . 111.

Physical Disability . . . . . iv, viii, 21, 22, 23, 27, 28, 29, 30, 31, 32, 33, 34-35, 36, 56, 60, 73, 78, 81, 83, 84, 86, 88, 89, 90, 92, 93, 94, 95, 98, 99, 136.

Physical Therapy . . . . . 79, 80, 82, 106.

Planning Committee, BRD . . . . . iv, 14, 16.

Pre-school Services . . . . . 68, 70.

Primary Caregiver . . . . . x, 4, 119-122.

Productivity . . . . . iv, v, vi, viii, 2, 4, 5, 7,, 9, 11, 39, 102, 109, 130, 131, 132, 151-171.

Protective/Legal Services . . . . . 79, 80, 86, 88.

Provision of Medical Equipment . . . . . (see "Payment/ Provision of Medical Equipment).

Psychosocial Rehabilitation . . . . . viii, 71, 72, 73.

Quality of Life . . . . . viii, 6, 8.

Race . . . . . 4, 19, 20, 119.

Recreational Facilities . . . . . 50, 52, 138, 139.

Regular School Room with Resource Room . . . . . 40, 67, 68, 143, 144, 146.

Regular Room in Regular School . . . . . 40, 67, 68, 143, 144, 146.

Rehabilitation Counseling, Dept. of (VCU) . . . . . ii, iv.

Rehabilitation Research and Training Center (VCU) . . . . . 17.

Rehabilitative Services, Dept. of . . . . . 25, 100, 101, 102.

Residential Services . . . . . (see "Housing").

Respite Care . . . . . 78, 79, 80, 81, 90-92, 106.

Restaurants, Visits to . . . . . 48, 52, 137.

Retiree Role . . . . . 10, 11, 18, 38, 49, 54, 56, 58, 166.

Rights of the Disabled . . . . . (see "Board for Rights of the Disabled").

Room and Board . . . . . (see "Housing").
Domiciliary

Schizophrenia . . . . . iv, 21.

School of Community . . . . . ii
and Public Affairs
(VCU)

Secondary Disability . . . . . 23-26, 88.

Self-Care . . . . . 4, 26, 27, 34-37,
(functional 58.
limitation)

Self-help or . . . . . v, x, 79, 80, 85,
Support Groups 86, 106, 108, 119
155.

Sensory Disability . . . . . iv, viii, 21,
22, 23, 27, 28,
29, 30, 31, 32,
34, 36, 37, 56,
60, 73, 81, 82,
83, 88, 89, 90,
92, 94, 95, 96,
97, 136.

Services and . . . . . 4, 5, 7, 9.
Satisfaction

Sex . . . . . (see "Gender").

Sheltered . . . . . vi.
Employment

Sheltered . . . . . 71.
Employment
(facility-
based)

Sheltered . . . . . 71.
Employment
(non-facility-
based)

Shopping Centers, . . . . . 137, 138.
Visits to

Social Choices . . . . . 111.

Social Security Disability Income (i.e., SSDI) . . . . . 101, 102.

Special Class, Regular School . . . . . 40, 68, 143, 144, 145, 146.

Special Needs Adoption . . . . . 91, 92, 98.

Special School (Day) . . . . . 40, 67, 68, 144, 145, 146.

Special School (Residential) . . . . . 67, 68, 144, 145, 146.

Speech Impairment . . . . . 23, 24, 25.

Spinal Bifida . . . . . 21, 23, 24.

Spinal Cord Injury . . . . . 21, 23, 24.

Sporting Events, Visits to . . . . . 48, 50, 138, 139.

Spouse Role . . . . . xii, 10, 11, 18, 28, 38, 49, 54, 56, 58, 59.

SSDI . . . . . (see "Social Security Disability Income").

SSI . . . . . (see "Supplemental Security Income").

Statewide Planning . . . . . 6, 7, 8, 9.

Student Role . . . . . x, xii, 10, 11, 37, 38, 39-47, 56, 58, 166.

Summer School . . . . . 68, 69, 70, 106, 156, 157, 159.

Supervised Home or Apartment . . . . . (see "Housing").

Supplemental Security Income (i.e., SSI) . . . . . 100, 101, 102.

Supported Employment . . . . . 71.

Technical and Vocational Education . . . . . 43, 44, 46, 57, 67, 68, 70, 72, 73, 106, 156, 157, 158, 159.

Theater (Live), Visits to . . . . . 48, 50, 139.

Transportation . . . . . 5, 6, 7,8, 9, 60, 75-78, 106, 107, 158.

Transportation Training . . . . . viii, 77.

Vehicle Modification . . . . . 77, 78.

Virginia Community College System . . . . . ii.

Virginia Institute for Developmental Disabilities (VCU) . . . . . 5, 15.

Visiting Nurse . . . . . (see "Home Health Aide/Visiting Nurse").

Visual and Hearing Impairment . . . . . (see "Hearing and Visual Impairment").

Visual Impairment . . . . . (see "Blindness and Severe Visual Impairment").

Vocational and Adult Day Services . . . . . 60, 70-73.

Vocational Education . . . . . (see "Technical and Vocational Education").

Voting . . . . . 155.

Work Activities, Prevocational . . . . . 71.

Work Adjustment . . . . . 71.

Worker Role . . . . . x, 10, 11, 18, 28, 38, 47, 49, 51, 52-53, 56, 58, 59, 76.

Work Modification . . . . . (see "Onsite Work Modification").

Work Settings . . . . . 115, 148, 160-168.

Appendix A

# FINAL SURVEY INSTRUMENT

A NATIONAL SURVEY OF CONSUMERS OF SERVICES FOR

INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

Submitted to:

National Association of Developmental Disabilities Councils
1234 Massachusetts Avenue, NW
Suite 103
Washington, DC 20005

Submitted by:

Temple University
Developmental Disabilities Center/UAP
Research and Quality Assurance Group
9th Floor Ritter Annex
Philadelphia, PA 19122

September 1, 1988

This is the final version of the National Consumer Survey Instrument. For the sake of simplicity, the survey is divided into sections. The sections are:

A) Eligibility/Screening
B) Demographics
C) Services and Satisfaction
D) Independence
E) Integration
F) Productivity
G) Supports/Services/Assistance Needed

For clarification, the surveyors should read the accompanying surveyors' guide.
If the individual is 16 years or older, s/he may respond to the survey. If the individual is less than 16, a surrogate should be consulted.

____ ____ ____ Consumer ID
(To be assigned by by each state)

____ ____ Surveyor ID
(To be assigned by each state)

_____ Region ID
(Assigned by the Individual State)

1) Northern Virginia
2) Tidewater
3) Central
4) Southwest Virginia

## A. ELIGIBILITY/SCREENING

These items will generally be asked over the telephone with the individual or someone (such as a parent or guardian) who can set up a personal interview with the the individual. If the screening is successful, arrange for a personal interview.

1. How old are you (the individual)?

   — —

2. Did your (the individual's) disability begin before the age of 22?

   ◯
   1 = Yes
   2 = No
   3 = Don't Know

   (If the answer is 2 or 3, terminate the screening process)

3. What is the primary medical diagnosis or description for your (the individual's) disability?

   1 = None
   2 = Autism
   3 = Blindness/severe visual impairment
   — — 4 = Cerebral palsy
   5 = Cystic fibrosis
   6 = Deafness/severe hearing impairment
   7 = Emotional (including chronic mental illness)
   8 = Epilepsy/seizure disorder
   9 = Head injury
   10 = Mental retardation
   11 = Multiple sclerosis
   12 = Muscular dystrophy
   13 = Orthopedic impairment
   14 = Speech/language impairment
   15 = Spina bifida
   16 = Spinal cord injury
   17 = Deafness and Blindness
   18 = Other neurological impairment
   19 = Other(s), such as learning disability, developmental delay, etc. please specify: _____
   _____

   (If the answer is none, terminate the screening process)

4. What other disabilities do you (the individual) also experience? Circle all that apply.

1 = None
2 = Autism
3 = Blindness/severe visual impairment
4 = Cerebral palsy
5 = Cystic fibrosis
6 = Deafness/severe hearing impairment
7 = Emotional (including chronic mental illness)
8 = Epilepsy/seizure disorder
9 = Head injury
10 = Mental retardation
11 = Multiple sclerosis
12 = Muscular dystrophy
13 = Orthopedic impairment
14 = Speech/language impairment
15 = Spina bifida
16 = Spinal cord injury
17 = Deafness and Blindness
18 = Other neurological impairment
19 = Other health conditions, such as cardiac, gastrointestinal, etc., please specify: _____
20 = Other(s), please specify: _____
_____
21 = Behavior problems

These functional screening items are subjective, but must be based on reality. The surveyor should ask both the consumer and the surrogate, if necessary, and then make judgments. In asking the questions below about children under the age of 18, the level of assistance needs to be judged on the basis of children without disabilities (i.e., "an unusual amount of assistance"). If the needs of the child are the same as those for a child without disabilities, the responses should be "none," in terms of the amount of assistance needed.

5. How much assistance or help do you (the individual) need in self care (e.g., bathing, grooming, eating)?

0 = None
1 = A little
2 = A lot (Substantial)

6. How much assistance or help do you (the individual) need from people or assistive devices in communicating to and understanding others?

0 = None
1 = A little
2 = A lot (Substantial)

7. How much assistance or help do you (the individual) need in acquiring new skills or behaviors (learning new things)?

0 = None
1 = A little
2 = A lot (Substantial)

8. How much assistance or help from people or assistive devices (e.g., wheelchair) do you (the individual) need in moving from place to place? (NOTE: This question refers to personal mobility, not need for transportation.)

0 = None
1 = A little
2 = A lot (Substantial)

9. How much assistance or help do you (the individual) need in managing your (the individual's) life, making decisions, and protecting your (the individual's) own interests?

0 = None
1 = A little
2 = A lot (Substantial)

(The following two questions, 10 and 11, should be reserved for individuals age 18 and older.)

10. How much assistance or help do you (the individual) or would you (the individual) need in order to live on your (their) own?

0 = None
1 = A little
2 = A lot (Substantial)
9 = NA (child)

11. How much assistance or help do you (the individual) need to maintain a source of income (generally through employment) sufficient to support yourself (the individual)?

0 = None
1 = A little
2 = A lot (Substantial)
9 = NA (child)

Adults: If an adult does not score "2"s on at least three of the items 5 through 11, terminate the screening.

Children under 18: If the child does not score "2"s on at least two of the items 5 through 9, terminate the screening.

The surveyor should review the answers to the screening when s/he is on site.

## B. DEMOGRAPHICS

For each of the questions, enter the most appropriate response either in the box to the left of the question, or in the spaces provided. It is not necessary to enter lead zeroes (e.g., if date of birth is June 1, 1959 it may be entered as 06/01/59 or 6/1/59.)

1. If a surrogate is assisting with responses to this survey, what is the surrogate's relationship to the individual?

1 = Parent/Spouse/Other Relative
2 = Other Surrogate (substitute or foster family member)
3 = Service Provider
4 = Friend or Advocate
5 = Other (please specify) _____
9 = NA (no surrogate is assisting the individual)

2. In what state, town and zip code do you (the individual) live?

_____

Town/City State Zip Code

3. What is your (the individual's) exact date of birth?

____ ____/____ ____/____ ____
month day year

4. What is your (the individual's) marital status?

1 = Never married
2 = Married
3 = Separated or divorced
4 = Widowed

5. What is your (the individual's) gender?

1 = Male
2 = Female

6. Approximately how many years did you (the individual) spend in each of the following educational settings? (States may wish to enter the names of their specific educational options here.) The purpose of this question is to find out the total number of years the individual spent in school.

| | |
|---|---|
| Early Intervention | __ __ |
| Preschool | __ __ |
| Elementary School | __ __ |
| Junior High/Middle School | __ __ |
| High School | __ __ |
| Trade or Vocational School | __ __ |
| College | __ __ |
| Graduate or Professional | __ __ |
| Homebound Education | __ __ |
| Special School or Program with no grades | __ __ |
| Type of setting unknown (enter number of years) | __ __ |

7. What was the last year you (the individual) attended school?

__ __ __ __

8. Was <u>most</u> of the education received in:

1. Special School (Residential-during academic year only)
2. Special School (Day)
3. Special Class in a Regular School
4. Resource Room in a Regular School
5. Regular Class in a Regular School
6. Homebound Education
7. Special Residential School Out of State
8. Residential Facility for Persons with Disabilities
9. Residential Facility for Persons with Mental Illness, Challenging Behavior
0. Not Applicable (i.e., person received no formal education)

9. Which of the following best describes your (the individual's) race?

| | | |
|---|---|---|
| | 1. White | 10. Asian Indian |
| | 2. Black or Negro | 11. Hawaiian |
| | 3. Hispanic | 12. Guamanian |
| ___ | 4. Japanese | 13. Samoan |
| | 5. Chinese | 14. Eskimo |
| | 6. Filipino | 15. Aleut |
| | 7. Korean | 16. Other (Specify): |
| | 8. Vietnamese | |
| | 9. (Amer) Indian | |

_____ _____
(print tribe):

10. How many times have you (the individual) changed addresses in the past five years (enter actual number)?

___ ___

11. Who would best be called a "primary caregiver" for you (the individual)? Circle one.

1 = You (The Individual)
2 = Parent/Spouse/Other Relative
3 = Foster Family Member
4 = Legal Guardian
5 = Friend or Advocate
6 = Paid Personal Care Attendant
7 = Service Provider
8 = Other (please specify) _____

12. Are you (the individual) a member of a consumer/advocacy group such as the Association for Retarded Citizens, The National Head Injury Foundation, The National Alliance for the Mentally Ill, United Cerebral Palsy, The Epilepsy Foundation of America, People First, or any other groups?

1 = Yes (Specify)_____
0 = No

13. Is anyone in your (the individual's) home a member of a consumer/advocacy group?

1 = Yes (Specify)_____
0 = No
9 = Don't Know or Individual Lives Alone

14. Is anyone in your immediate family a member of a consumer/advocacy group?

1 = Yes (Specify)_____
0 = No
9 = Don't Know or No Family

## C. SERVICES AND SATISFACTION

Surveyors may introduce this section in this way: The next few questions are about your (the individual's) feelings. We want to hear about where you (the individual) live, what you (the individual) do, and what services you (the individual) are currently receiving.

1. Are you (the individual) satisfied living here, or would you like to live someplace else?

   1. Stay here
   2. Stay here but with changes, e.g., different roommates, different staff, more privacy
   3. Move to a different place (geographically)
   4. Move to a different place (Type of setting)
   8. No opinion
   9. Don't know or no answer

2. If you (the individual) are working (work includes day programs, sheltered workshops, etc.): Please tell me how true this is about your (the individual's) job. Getting to and from work is convenient. Is this very true, somewhat true, neither true nor untrue, not very true or not true at all? If the person is not working skip to question #4.

   1. Very true
   2. Somewhat true
   3. Neither true nor untrue
   4. Not very true
   5. Not true at all
   8. No opinion
   9. Not applicable

3. All things considered, how satisfied are you (the individual) with your job?

   1. Very satisfied
   2. Somewhat satisfied
   3. Neither satisfied nor dissatisfied
   4. Somewhat dissatisfied
   5. Very dissatisfied
   8. No opinion
   9. Not applicable

4. If you (the individual) are in school: Please tell me how true this is about school. Getting to and from school is convenient. How true is this?

1. Very true
2. Somewhat true
3. Neither true nor untrue
4. Not very true
5. Not true at all
8. No opinion
9. Not applicable

5. All things considered, how satisfied are you (the individual) with school?

1. Very satisfied
2. Somewhat satisfied
3. Neither satisfied nor dissatisfied
4. Somewhat dissatisfied
5. Very dissatisfied
8. No opinion
9. Not applicable

6. If the individual is not working or in school: Please tell me how true this is about getting around the place where you (the individual) live and going from place to place. Getting around is convenient. How true is this?

1. Very true
2. Somewhat true
3. Neither true nor untrue
4. Not very true
5. Not true at all
8. No opinion
9. Not applicable

For the next two questions, surveyors may use the word "happy" as a prompt for ascertaining level of satisfaction. If surrogates are responding, they should be responding to their perceptions of the level of satisfaction of the individual with a disability. If it is absolutely impossible to measure or assess level of satisfaction, these three items may be left blank.

7. How satisfied are you (the individual) with life in general?

1. Very satisfied
2. Somewhat satisfied
3. Neither satisfied nor dissatisfied
4. Somewhat dissatisfied
5. Very dissatisfied
8. No opinion

8. Overall, how satisfied are you (the individual) with the ways you spend your spare time?

1. Very satisfied
2. Somewhat satisfied
3. Neither satisfied nor dissatisfied
4. Somewhat dissatisfied
5. Very dissatisfied
8. No opinion

9. Getting around in my (the individual's) spare time is convenient. How true is this statement?

1. Very true
2. Somewhat true
3. Neither true nor untrue
4. Not very true
5. Not true at all
8. No opinion

10. What has been your (the individual's) experience with the following programs or agencies? State specific names may be added under specific Federal program names.

1 = No experience
2 = Application is pending
3 = Application was denied
4 = Received and was satisfied
5 = Received and was dissatisfied
9 = Don't know

a. Aid to Families with Dependent Children (AFDC) ___

_____

b. Department of Rehabilitative Services ___

_____

c. Education (Regular or Special) ___

_____

d. Medicaid (Department of Medical Assistance Services) ___

_____

e. Department of Mental Health, Mental Retardation & Substance Abuse Services ___

_____

f. Independent Living Centers (CIL) ___

_____

g. Supplemental Security Income (SSI) ___

_____

1 = No experience
2 = Application is pending
3 = Application was denied
4 = Received and was satisfied
5 = Received and was dissatisfied
9 = Don't know

h. Social Security Disability Income (SSDI) ___

i. Maternal And Child Health (MCH) ___

j. Children's Specialty Services ___

k. Community Mental Health Services ___

l. HUD Section 8 Rent Certificate ___

## 11. Satisfaction With Services the Person is Currently Receiving

Refer to Appendix 1 in the Surveyor's Guide for a description of services.

For services the person is currently receiving, obtain the person's (or the surrogate's) rating of satisfaction with the service on this five point scale:

1 = VERY SATISFIED
(SERVICE IS VERY GOOD)
2 = SATISFIED
(SERVICE IS GOOD)
3 = IN BETWEEN OR NEUTRAL
(SERVICE IS NEITHER GOOD NOR BAD)
4 = DISSATISFIED
(SERVICE IS BAD)
5 = VERY DISSATISFIED
(SERVICE IS VERY BAD)

A few services are very short in duration. They are marked with the notation "(recently)". For these services, obtain a satisfaction rating if the service was received within the past year.

*ONLY* for services that are rated "DISSATISFIED" or "VERY DISSATISFIED," ask for the main reason for the dissatisfaction, and code the reason in these categories:

1 = NOT RECEIVING ENOUGH
2 = POOR QUALITY
3 = TOO EXPENSIVE
4 = NOT SUITED TO INDIVIDUAL NEEDS
5 = DOES NOT HELP
6 = DOES NOT RESPECT PERSONAL DIGNITY
7 = TRANSPORTATION
8 = UNDERSTAFFED
9 = NOT INTEGRATED
0 = ANY OTHER REASON (SPECIFY IN MARGIN)

## SATISFACTION WITH SERVICES

SATISFACTION

1 = VERY SATISFIED (SERVICE IS VERY GOOD)
2 = SATISFIED (SERVICE IS GOOD)
3 = IN BETWEEN OR NEUTRAL (SERVICE IS NEITHER GOOD NOR BAD)
4 = DISSATISFIED (SERVICE IS BAD)
5 = VERY DISSATISFIED (SERVICE IS VERY BAD)

REASONS FOR DISSATISFACTION

1 = NOT RECEIVING ENOUGH
2 = POOR QUALITY
3 = TOO EXPENSIVE
4 = NOT SUITED TO INDIVIDUAL NEEDS
5 = DOES NOT HELP
6 = DOES NOT RESPECT PERSONAL DIGNITY
7 = TRANSPORTATION
8 = UNDERSTAFFED
9 = NOT INTEGRATED
0 = ANY OTHER REASON (SPECIFY IN MARGIN)

| | | | How Satisfied? | If Dissatisfied, Why? |
|---|---|---|---|---|
| 1.0 | CASE COORDINATION SERVICES | | | |
| 1.1 | Assessment/Individual Plan Development (recently) | 1.1 | ____ | ____ |
| 1.2 | Case Management | 1.2 | ____ | ____ |
| 1.3 | Information and Referral (recently) | 1.3 | ____ | ____ |
| 2.0 | RESIDENTIAL SERVICES | | | |
| 2.1 | Institution (50 or fewer people) | 2.1 | ____ | ____ |
| 2.2 | Institution (more than 50 people) | 2.2 | ____ | ____ |
| 2.3 | Nursing home (50 or fewer people) | 2.3 | ____ | ____ |
| 2.4 | Nursing home (more than 50 people) | 2.4 | ____ | ____ |
| 2.5 | Group Home or Apartment, 16 or More People | 2.5 | ____ | ____ |
| 2.6 | Group Home or Apartment, 10 to 15 People | 2.6 | ____ | ____ |
| 2.7 | Group Home or Apartment, 6 to 9 People | 2.7 | ____ | ____ |
| 2.8 | Group Home or Apartment, 1 to 5 People | 2.8 | ____ | ____ |
| 2.9 | Supervised Home or Apartment | 2.9 | ____ | ____ |
| 2.10 | Room and Board Domiciliary Care | 2.10 | ____ | ____ |
| 2.11 | Family Care (Substitute or Foster Family) (Only one of the above, 2.1-2.11 can be checked) | 2.11 | ____ | ____ |
| 2.12 | Homemaking Assistance or Training | 2.12 | ____ | ____ |
| 2.13 | Housing Subsidy (e.g., Section 8) | 2.13 | ____ | ____ |
| 2.14 | Architectural Modifications | 2.14 | ____ | ____ |

SATISFACTION

1 = VERY SATISFIED (SERVICE IS VERY GOOD)
2 = SATISFIED (SERVICE IS GOOD)
3 = IN BETWEEN OR NEUTRAL (SERVICE IS NEITHER GOOD NOR BAD)
4 = DISSATISFIED (SERVICE IS BAD)
5 = VERY DISSATISFIED (SERVICE IS VERY BAD)

REASONS FOR DISSATISFACTION

1 = NOT RECEIVING ENOUGH
2 = POOR QUALITY
3 = TOO EXPENSIVE
4 = NOT SUITED TO INDIVIDUAL NEEDS
5 = DOES NOT HELP
6 = DOES NOT RESPECT PERSONAL DIGNITY
7 = TRANSPORTATION
8 = UNDERSTAFFED
9 = NOT INTEGRATED
0 = ANY OTHER REASON (SPECIFY IN MARGIN)

| | | | How Satisfied? | If Dissatisfied, Why? |
|---|---|---|---|---|
| 3.0 | EDUCATIONAL SERVICES | | | |
| 3.1 | Early Intervention Services | 3.1 | ____ | ____ |
| 3.2 | Preschool Services | 3.2 | ____ | ____ |
| 3.3 | Regular Class in a Regular School | 3.3 | ____ | ____ |
| 3.4 | Regular Class and Resource Room | 3.4 | ____ | ____ |
| 3.5 | Special Class in a Regular School | 3.5 | ____ | ____ |
| 3.6 | Special School (Day) | 3.6 | ____ | ____ |
| 3.7 | Special School (Residential) | 3.7 | ____ | ____ |
| 3.8 | Homebound Education | 3.8 | ____ | ____ |
| 3.9 | After School Tutor | 3.9 | ____ | ____ |
| 3.10 | Related Services (e.g., aide, attendant) | 3.10 | ____ | ____ |
| 3.11 | Summer School/Programs | 3.11 | ____ | ____ |
| 3.12 | Adult Literacy/Basic Education | 3.12 | ____ | ____ |
| 3.13 | Vocational/Technical or Vocational Education | 3.13 | ____ | ____ |
| 3.14 | Post Secondary Education | 3.14 | ____ | ____ |
| 4.0 | VOCATIONAL AND OTHER ADULT DAY SERVICES | | | |
| 4.1 | Adult Day Service, Non-Developmental | 4.1 | ____ | ____ |
| 4.2 | Adult Day Service, Developmental/Habilitative | 4.2 | ____ | ____ |
| 4.3 | Partial Hospitalization | 4.3 | ____ | ____ |
| 4.4 | Psychosocial Rehabilitation | 4.4 | ____ | ____ |
| 4.5 | Day Treatment | 4.5 | ____ | ____ |
| 4.6 | Work Activities or Prevocational | 4.6 | ____ | ____ |
| 4.7 | Work Adjustment | 4.7 | ____ | ____ |
| 4.8 | Sheltered Employment, facility based | 4.8 | ____ | ____ |
| 4.9 | Sheltered Employment, non-facility based (e.g., enclaves, mobile work crews) | 4.9 | ____ | ____ |
| 4.10 | Supported Employment (Paid, integrated, ongoing support) | 4.10 | ____ | ____ |
| 4.11 | Competitive Employment (Time Limited Services) | 4.11 | ____ | ____ |
| 4.12 | Job Placement Services | 4.12 | ____ | ____ |
| 4.13 | On-site modifications to the work site | 4.13 | ____ | ____ |
| 4.14 | On-site aide/attendant | 4.14 | ____ | ____ |

SATISFACTION

1 = VERY SATISFIED
(SERVICE IS VERY GOOD)
2 = SATISFIED
(SERVICE IS GOOD)
3 = IN BETWEEN OR NEUTRAL
(SERVICE IS NEITHER GOOD NOR BAD)
4 = DISSATISFIED
(SERVICE IS BAD)
5 = VERY DISSATISFIED
(SERVICE IS VERY BAD)

REASONS FOR DISSATISFACTION

1 = NOT RECEIVING ENOUGH
2 = POOR QUALITY
3 = TOO EXPENSIVE
4 = NOT SUITED TO INDIVIDUAL NEEDS
5 = DOES NOT HELP
6 = DOES NOT RESPECT PERSONAL DIGNITY
7 = TRANSPORTATION
8 = UNDERSTAFFED
9 = NOT INTEGRATED
0 = ANY OTHER REASON (SPECIFY IN MARGIN)

| | | | How Satisfied? | If Dissatisfied, Why? |
|---|---|---|---|---|
| 5.0 | HEALTH SERVICES | | | |
| 5.1 | General/Special Hospitals (recently) | 5.1 | ____ | ____ |
| 5.2 | Emergency Health Services (recently) | 5.2 | ____ | ____ |
| 5.3 | General Medical Services (recently) | 5.3 | ____ | ____ |
| 5.4 | Dental Services (recently) | 5.4 | ____ | ____ |
| 5.5 | Health Insurance (private) | 5.5 | ____ | ____ |
| 5.6 | Medicaid (Medical Care) | 5.6 | ____ | ____ |
| 5.7 | Payment for or Provision of Medical Equipment/Supplies | 5.7 | ____ | ____ |
| 5.8 | Payment for or Provision of Medication | 5.8 | ____ | ____ |
| 5.9 | Genetic Counseling/Screening (recently) | 5.9 | ____ | ____ |
| 6.0 | INDIVIDUAL SUPPORT SERVICES | | | |
| 6.1 | Respite Care, In Home (recently) | 6.1 | ____ | ____ |
| 6.2 | Respite Care, Out of Home (recently) | 6.2 | ____ | ____ |
| 6.3 | Behavior Management Assistance/Training | 6.3 | ____ | ____ |
| 6.4 | Mental Health or Counseling Services (recently) | 6.4 | ____ | ____ |
| 6.5 | Protective or Legal Services (recently) | 6.5 | ____ | ____ |
| 6.6 | Physical Therapy or Related Services | 6.6 | ____ | ____ |
| 6.7 | Occupational Therapy or Services | 6.7 | ____ | ____ |
| 6.8 | Communication and Language Services | 6.8 | ____ | ____ |
| 6.9 | Attendant Care | 6.9 | ____ | ____ |
| 6.10 | Community Living Assistance or Training | 6.10 | ____ | ____ |
| 6.11 | Home Health Aides or Visiting Nurse | 6.11 | ____ | ____ |
| 6.12 | Adaptive Equipment/Assistive Devices & Training (recently) | 6.12 | ____ | ____ |
| 6.13 | Income Assistance (i.e., SSI) | 6.13 | ____ | ____ |
| 6.14 | Food Assistance/Food Stamps | 6.14 | ____ | ____ |
| 6.15 | Homemaker/Chore Services | 6.15 | ____ | ____ |
| 6.16 | Cooking/Meals on Wheels | 6.16 | ____ | ____ |
| 6.17 | Companion/Friend-Advocate Program | 6.17 | ____ | ____ |
| 6.18 | Self Help/Support Groups | 6.18 | ____ | ____ |
| 6.19 | Financial Management Assistance | 6.19 | ____ | ____ |
| 6.20 | Community Support Services | 6.20 | ____ | ____ |

| SATISFACTION | REASONS FOR DISSATISFACTION |
|---|---|
| 1 = VERY SATISFIED (SERVICE IS VERY GOOD) | 1 = NOT RECEIVING ENOUGH |
| 2 = SATISFIED (SERVICE IS GOOD) | 2 = POOR QUALITY |
| 3 = IN BETWEEN OR NEUTRAL (SERVICE IS NEITHER GOOD NOR BAD) | 3 = TOO EXPENSIVE |
| 4 = DISSATISFIED (SERVICE IS BAD) | 4 = NOT SUITED TO INDIVIDUAL NEEDS |
| 5 = VERY DISSATISFIED (SERVICE IS VERY BAD) | 5 = DOES NOT HELP |
| | 6 = DOES NOT RESPECT PERSONAL DIGNITY |
| | 7 = TRANSPORTATION |
| | 8 = UNDERSTAFFED |
| | 9 = NOT INTEGRATED |
| | 0 = ANY OTHER REASON (SPECIFY IN MARGIN) |

| | | | How Satisfied? | If Dissatisfied, Why? |
|---|---|---|---|---|
| 7.0 | TRANSPORTATION | | | |
| 7.1 | Transp'n to and from work, school, day activity | 7.1 | ____ | ____ |
| 7.2 | Transp'n to and from non-daily services/activities (e.g., medical appointments, shopping) | 7.2 | ____ | ____ |
| 7.3 | Transp'n for leisure time (weekdays) | 7.3 | ____ | ____ |
| 7.4 | Transp'n for leisure time (weekends) | 7.4 | ____ | ____ |
| 7.5 | Vehicle Modification | 7.5 | ____ | ____ |
| 7.6 | Transportation Training (driver's education, use of public transportation, etc.) | 7.6 | ____ | ____ |

For the items in the CAREGIVER SUPPORT SERVICES section, the caregiver should always be consulted. A caregiver is intended to mean someone other than the consumer. The questions are meant to be asked of a family member or other non-paid person.

| | | | | |
|---|---|---|---|---|
| 8.0 | CAREGIVER SUPPORT SERVICES | | | |
| 8.1 | Respite Care, In Home (recently) | 8.1 | ____ | ____ |
| 8.2 | Respite Care, Outside Home (recently) | 8.2 | ____ | ____ |
| 8.3 | Child Day Care | 8.3 | ____ | ____ |
| 8.4 | Homemaker/Chore Services | 8.4 | ____ | ____ |
| 8.5 | Behavior Management Assistance/Training | 8.5 | ____ | ____ |
| 8.6 | Family Counseling (recently) | 8.6 | ____ | ____ |
| 8.7 | Parent Training (recently) | 8.7 | ____ | ____ |
| 8.8 | Family Education (recently) | 8.8 | ____ | ____ |
| 8.9 | Genetic Screening and/or Counseling (recently) | 8.9 | ____ | ____ |
| 8.10 | Family Cash Assistance | 8.10 | ____ | ____ |
| 8.11 | Family Support Services (Other _____) | 8.11 | ____ | ____ |
| 8.12 | Adult Day Care | 8.12 | ____ | ____ |
| 8.13 | Family Support Group | 8.13 | ____ | ____ |
| 8.14 | Special Needs Adoption | 8.14 | ____ | ____ |

| SATISFACTION | REASONS FOR DISSATISFACTION |
|---|---|
| 1 = VERY SATISFIED (SERVICE IS VERY GOOD) | 1 = NOT RECEIVING ENOUGH |
| 2 = SATISFIED (SERVICE IS GOOD) | 2 = POOR QUALITY |
| 3 = IN BETWEEN OR NEUTRAL (SERVICE IS NEITHER GOOD NOR BAD) | 3 = TOO EXPENSIVE |
| 4 = DISSATISFIED (SERVICE IS BAD) | 4 = NOT SUITED TO INDIVIDUAL NEEDS |
| 5 = VERY DISSATISFIED (SERVICE IS VERY BAD) | 5 = DOES NOT HELP |
| | 6 = DOES NOT RESPECT PERSONAL DIGNITY |
| | 7 = TRANSPORTATION |
| | 8 = UNDERSTAFFED |
| | 9 = NOT INTEGRATED |
| | 0 = ANY OTHER REASON (SPECIFY IN MARGIN) |

| | | | How Satisfied? | If Dissatisfied, Why? |
|---|---|---|---|---|
| 9.0 | OTHER SERVICES | | | |
| 9.1 | Recreation/Leisure Services | 9.1 | ____ | ____ |
| 9.2 | _____(Specify) | 9.2 | ____ | ____ |
| 9.3 | _____(Specify) | 9.3 | ____ | ____ |

## D. INDEPENDENCE

1. Do you (the individual) own your home or hold the lease for your house or apartment? For children under 16, code 0.

1 = Yes
0 = No
9 = Don't Know

2. Did you (the individual) choose the place where you (the individual) live?

1 = Yes, the individual chose the place unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown (including court)

3. Did you (the individual) choose your (the individual's) attendant and/or residential support staff?

1 = Yes, the individual chose unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

4. Did you (the individual) choose your (the individual's) roommate(s)/housemate(s)?

1 = Yes, the individual chose unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

5. Did you (the individual) choose your (the individual's) job (or what you (the individual) do on weekdays)?

1 = Yes, the individual chose unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

6. Do you (the individual) usually choose what you (the individual) do on weekends and evenings?

1 = Yes, the individual chooses unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

7. Do you (the individual) give your own consent for medical care?

1 = Yes, unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

8. Do you (the individual) determine what clothes you (the individual) wear?

1 = Yes, unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

9. Do you (the individual) usually choose your (the individual's) friends and acquaintances?

1 = Yes, unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

10. Do you (the individual) usually decide how your (the individual's) personal space (home, apartment, bedroom, etc.) is decorated?

1 = Yes, unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

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11. Do you (the individual) go to the bank and deposit and withdraw money?

1 = Yes, unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

12. Do you (the individual) pay your own rent, gas/electric, and phone bills?

1 = Yes, unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

13. Do you (the individual) usually decide what things you (the individual) buy with your (the individual's) spending money ?

1 = Yes, unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

14. Do you (the individual) determine which agencies and organizations provide services and support to you (the individual)?

1 = Yes, unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

For this question, the first sentence is there only to familiarize the surveyor with the language in the Act. You should only read the last sentence. A good prompt might be to ask whether the individual makes choices in his/her life.

15. According to the Developmental Disabilities Assistance and Bill of Rights Act as amended in 1987, independence means "the extent to which persons with developmental disabilities exert control and choice over their own lives." On a scale of 1 to 5, with 1 being totally independent and 5 being totally dependent, how independent do you (the individual) think you are?

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Totally independent | | | | Not at all independent |

16. How important is it to you (the individual) to be independent?

1. Very important
2. Somewhat important
3. Neutral
4. Somewhat unimportant
5. Not important at all

## E. INTEGRATION

1. Did you (the individual) vote in the most recent general election?

1 = Yes
0 = No
9 = Not Applicable; consumer under 18 years old

2. About how often do you (the individual) do each of the following:

1 = More than twice a week
2 = Twice a week
3 = Once a week
4 = 2-3 times a month
5 = Once a month
6 = Less than once a month
7 = Never
9 = Not sure or refused

Would you like to do this activity more often, less often, or is this the right amount?

1 = More Often
2 = Right Amount
3 = Less Often

| | Frequency | Satis W/ Freq. |
|---|---|---|
| a. Visit with close friends, relatives or neighbors | — | — |
| b. Visit a supermarket or food store | — | — |
| c. Go to a restaurant | — | — |
| d. Go to church or synagogue | — | — |
| e. Go to a shopping center, mall or other retail store to shop | — | — |
| f. Go to bars, taverns, etc. | — | — |
| g. Go to the bank | — | — |

3. Approximately how many times did you (the individual) go to each of the following in the past 12 months? (NOTE: DO NOT INCLUDE EVENTS THAT WERE SPECIFICALLY FOR PEOPLE WITH DISABILITIES.)

1 = More than 20 times
2 = 11-20 times
3 = 6-10 times
4 = 4-5 times
5 = 2-3 times
6 = Once
7 = Never in the past 12 months
9 = Unknown

Would you like to do this activity more often, less often, or is this the right amount?

1 = More Often
2 = Right Amount
3 = Less Often

| | Frequency | Satis W/ Freq. |
|---|---|---|
| a. Go to the movies | ___ | ___ |
| b. Go to live theatre performance | ___ | ___ |
| c. Go to live popular music performances | ___ | ___ |
| d. Go to a sports event | ___ | ___ |
| e. YMCA/YWCA/YMHA or other athletic clubs/facilities | ___ | ___ |
| f. Community/civic groups | ___ | ___ |

This question should be answered by the surveyor. You may have to ask a few questions and observe. The key here is, does this house fit into the community, and could it be purchased by any family?

4. In what kind of place does the individual currently live?

1 = Single family home (or mobile home) in a neighborhood
2 = Single family home (or mobile home) in a rural area
3 = Multi-family home or apartment in a community setting
4 = Rooming house or residential hotel
5 = Living facility specifically built or extensively renovated that would only be suitable for use as a congregate care facility
6 = Nursing home
7 = Institution

5. How many other individuals live at the same address as you (the individual)?

   a. Family members/relatives ___ ___

   b. Personal care attendants ___ ___

   c. Other paid staff who live here always ___ ___

   d. Other paid staff who live here sometimes ___ ___

   e. Other individuals with disabilities ___ ___ ___

   f. Other individuals without disabilities ___ ___

6. During the past few weeks have you (the individual) ever felt very lonely or remote from other people?

   1 = Yes
   0 = No
   9 = Unsure

7. I'd like to ask you (the individual) about the people who live around here, but not at this address or facility. As neighbors would you say they are very good, fairly good, neither good nor bad, not very good or not good at all?

   1. Very good
   2. Fairly good
   3. Neither good nor bad
   4. Not very good
   5. Not good at all
   9. Don't know or no opinion

8. Of the ten families that live closest to you (the individual) here, how many would you say you know by name?
   Enter exact number of families, 0 = none, through 10.

   ___ ___

9. Of these ten families that live close to you (the individual), how many have you ever visited with, either in their home or in yours?
   Enter exact number of families, 0 = none, through 10.

   ___ ___

10. Do you (the individual) have any friends/acquaintances who you see regularly who do not have a disability?

    1 = Yes
    0 = No

11. Do most of your (the individual's) friends have a disability?

1 = Yes
0 = No

For this question, the first sentence is there only to familiarize the surveyor with the language in the Act. You should only read the last sentence.

12. According to the Developmental Disabilities Assistance and Bill of Rights Act as amended in 1987, integration means, "the use by persons with developmental disabilities of the same community resources that are used by and available to other citizens, and participation by persons with developmental disabilities in the same community activities in which nondisabled citizens participate, together with regular contact with nondisabled citizens, and the residence by persons with developmental disabilities in homes or in home-like settings which are in proximity to community resources, together with regular contact with nondisabled citizens in their communities." Or, a scale of 1 to 5, with 1 being totally integrated and 5 being totally segregated, how integrated do you (the individual) think you are?

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Totally integrated | | | | Not at all integrated |

13. How important is it to you (the individual) to be integrated into the community?

1. Very important
2. Somewhat important
3. Neutral
4. Somewhat unimportant
5. Not important at all

## F. PRODUCTIVITY

1. Which of the following categories best describes your (the individual's) current situation: Are you (the individual) (read list):

   1. Working full-time for an employer, a workshop, or yourself
   2. Working part-time for an employer, a workshop, or yourself
   3. Unemployed but looking for work
   4. Unemployed but not looking for work
   5. Retired
   6. Completely unable to work because of health problem(s)
   7. Keeping house
   8. Full-time student, employment trainee, or participant in vocational rehabilitation
   9. Doing full or part-time volunteer work
   0. None of the above

2. Have you (the individual) ever worked for pay? (If the answer is 0 or 9, skip to question 10.)

   1 = Yes
   0 = No
   9 = Don't Know

3. How many hours in an average week do you (the individual) spend in working for pay?

   __ __
   (Enter number of hours; if none enter 0 and skip to question 7)

4. What was your (the individual's) gross pay last week? (If unknown, enter 999.)

   __ __ __ (enter in dollars)

5. What is your (the individual's) job title?
   (Job titles should be "forced" into one of the OES codes.)

   _____
   Job Title

   __ __ __ __ __ __ __ __ __
   (Select an OES code from the chart)

6. How long have you (the individual) had this job?
   If less than 1 year, code 01.

   __ __ (Enter number of years.)

(If this is the individual's first job skip to question 10.)

7. How many hours per week (on the average) did you (the individual) work at your prior job? Enter 99 if unknown.

___ ___ (Enter number of hours.)

8. What was your (the individual's) gross weekly pay (on the average) at your prior job? (Enter 999 if unknown.)

___ ___ ___ (enter in dollars)

9. What was the title of your (the individual's) prior job? Job titles should be "forced" into one of the OES codes.

_____
Job Title

__ __ __ __ __ __ __ __ __
(Select an OES code from the chart)

10. How many hours <u>last week</u> did you (the individual) spend doing house work in your own home?

___ ___ (Enter number of hours.)

11. How many hours <u>last</u> month did you (the individual) spend doing civic or community work or other volunteer work?

___ ___ (Enter number of hours.)

12. How many hours <u>last week</u> did you (the individual) spend helping family, friends, or neighbors?

___ ___ (Enter number of hours.)

For this question, the first sentence is there only to familiarize the surveyor with the language in the Act. You should only read the last sentence..

13. According to the Developmental Disabilities Assistance and Bill of Rights Act as amended in 1987, productivity means, "engagement in income-producing work by a person with developmental disabilities which is measured through improvements in income level, employment status, or job advancement, or, engagement by a person with developmental disabilities in work which contributes to a household or community." On a scale of 1 to 5, with 1 being very productive and 5 being not productive at all, how productive do you (the individual) think you are?

---

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Very Productive | | | | Not productive at all |

14. How important is it to you (the individual) to be productive?

1. Very important
2. Somewhat important
3. Neutral
4. Somewhat unimportant
5. Not important at all

## G. Supports/Services/Assistance Needed

In this section we want individuals to think about the best possible array of services that they could possibly receive. This may have nothing to do with services the person is currently receiving. Please ask individuals to think about what services they would need most to foster independence, integration and productivity.

Which of the following supports, services or other assistance would provide the most help to you in living, working or going to school, and participating in the community? For supports and services that you are not currently receiving, please code the reason you are not receiving the support, service, assistance now, and what the level of need is for the assistance. For services you would need and are currently receiving, code 0 under reason for not receiving.

LEVEL OF NEED

1 = NOT NEEDED AT ALL
2 = SLIGHT NEED
3 = MODERATE NEED
4 = STRONG NEED
5 = CRITICAL OR PRIMARY NEED
9 = DON'T KNOW

PRIMARY REASON FOR NOT RECEIVING THE SUPPORT, SERVICE OR ASSISTANCE

1 = NOT ELIGIBLE BY TYPE OR DEGREE OF DISABILITY
2 = NOT ELIGIBLE BECAUSE OF INCOME OR MEANS
3 = SERVICE IS TOO EXPENSIVE TO OBTAIN
4 = SERVICE IS NOT AVAILABLE IN THE AREA
5 = SERVICE THAT IS AVAILABLE IS NOT APPROPRIATE TO MY NEEDS OR DOESN'T LIKE THE SERVICE
6 = PERSON DIDN'T KNOW SERVICE EXISTED
7 = ON A WAITING LIST OR AVAILABILITY IS LIMITED
8 = ANY OTHER REASON
9 = UNKNOWN
0 = CURRENTLY RECEIVING SERVICE

SUPPORTS NEEDED

LEVEL OF NEED

1 = NOT NEEDED AT ALL
2 = SLIGHT NEED
3 = MODERATE NEED
4 = STRONG NEED
5 = URGENT OR PRIMARY NEED
9 = DON'T KNOW

REASON FOR NOT RECEIVING

1 = NOT ELIGIBLE BY TYPE OR DEGREE OF DISABILITY
2 = NOT ELIGIBLE BECAUSE OF INCOME OR MEANS
3 = SERVICE IS TOO EXPENSIVE TO OBTAIN
4 = SERVICE IS NOT AVAILABLE IN THE AREA
5 = SERVICE THAT IS AVAILABLE IS NOT APPROPRIATE TO NEEDS OR PERSON DOESN'T LIKE THE SERVICE
6 = PERSON DID NOT KNOW THE SERVICE EXISTED
7 = ON A WAITING LIST OR AVAILABILITY IS LIMITED
8 = ANY OTHER REASON
9 = UNKNOWN
0 = CURRENTLY RECEIVING SERVICE

| | | | Level of Need | Reason not Receiving |
|---|---|---|---|---|
| 1.0 | CASE COORDINATION SERVICES | | | |
| 1.1 | Case Management | 1.1 | ____ | ____ |
| 2.0 | RESIDENTIAL SUPPORTS | | | |
| 2.1 | Homemaking Assistance or Training | 2.1 | ____ | ____ |
| 2.2 | Housing Subsidy (e.g., Section 8) | 2.2 | ____ | ____ |
| 2.3 | Architectural Modifications | 2.3 | ____ | ____ |
| 3.0 | EDUCATIONAL SUPPORTS/SERVICES | | | |
| 3.1 | Early Intervention Services | 3.1 | ____ | ____ |
| 3.2 | Preschool Services | 3.2 | ____ | ____ |
| 3.3 | After School Tutor | 3.3 | ____ | ____ |
| 3.4 | Related Supports (e.g., aide, attendant) | 3.4 | ____ | ____ |
| 3.5 | Summer School/Programs | 3.5 | ____ | ____ |
| 3.6 | Adult Literacy/Basic Education | 3.6 | ____ | ____ |
| 3.7 | Vocational/Technical or Vocational Education | 3.7 | ____ | ____ |
| 3.8 | Post Secondary Education | 3.8 | ____ | ____ |
| 4.0 | EMPLOYMENT/VOCATIONAL/DAY SUPPORTS/SERVICES | | | |
| 4.1 | Employment Services (e.g., job coach) | 4.1 | ____ | ____ |
| 4.2 | Vocational Training Services | 4.2 | ____ | ____ |
| 4.3 | Psychosocial Rehabilitation | 4.3 | ____ | ____ |
| 4.4 | Adult/Child Day Care | 4.4 | ____ | ____ |
| 4.5 | Habilitation Services | 4.5 | ____ | ____ |
| 4.6 | On-site modifications at the work site | 4.6 | ____ | ____ |
| 4.7 | On-site aide/attendant | 4.7 | ____ | ____ |

LEVEL OF NEED

1 = NOT NEEDED AT ALL
2 = SLIGHT NEED
3 = MODERATE NEED
4 = STRONG NEED
5 = URGENT OR PRIMARY NEED
9 = DON'T KNOW

REASON FOR NOT RECEIVING

1 = NOT ELIGIBLE BY TYPE OR DEGREE OF DISABILITY
2 = NOT ELIGIBLE BECAUSE OF INCOME OR MEANS
3 = SERVICE IS TOO EXPENSIVE TO OBTAIN
4 = SERVICE IS NOT AVAILABLE IN THE AREA
5 = SERVICE THAT IS AVAILABLE IS NOT APPROPRIATE TO NEEDS OR PERSON DOESN'T LIKE THE SERVICE
6 = PERSON DID NOT KNOW THE SERVICE EXISTED
7 = ON A WAITING LIST OR AVAILABILITY IS LIMITED
8 = ANY OTHER REASON
9 = UNKNOWN
0 = CURRENTLY RECEIVING SERVICE

| | | Level of Need | Reason not Receiving |
|---|---|---|---|
| 5.0 | HEALTH SUPPORTS/SERVICES | | |
| 5.1 | General Medical Services | 5.1 ____ | ____ |
| 5.2 | Dental Services | 5.2 ____ | ____ |
| 5.3 | Health Insurance (Private) | 5.3 ____ | ____ |
| 5.4 | Payment for or Provision of Medical Equipment/Supplies | 5.4 ____ | ____ |
| 5.5 | Payment for or Provision of Medication | 5.5 ____ | ____ |
| 6.0 | INDIVIDUAL SUPPORT SERVICES | | |
| 6.1 | Respite Care, In Home | 6.1 ____ | ____ |
| 6.2 | Respite Care, Out of Home | 6.2 ____ | ____ |
| 6.3 | Behavior Management Assistance/Training | 6.3 ____ | ____ |
| 6.4 | Mental Health or Counseling Services | 6.4 ____ | ____ |
| 6.5 | Protective or Legal Services | 6.5 ____ | ____ |
| 6.6 | Physical Therapy or Related Services | 6.6 ____ | ____ |
| 6.7 | Occupational Therapy or Services | 6.7 ____ | ____ |
| 6.8 | Communication and Language Services | 6.8 ____ | ____ |
| 6.9 | Attendant Care | 6.9 ____ | ____ |
| 6.10 | Community Living Assistance or Training | 6.10 ____ | ____ |
| 6.11 | Home Health Aides or Visiting Nurse | 6.11 ____ | ____ |
| 6.12 | Adaptive Equipment/Assistive Devices and Training | 6.12 ____ | ____ |
| 6.13 | Income Assistance (i.e., SSI) | 6.13 ____ | ____ |
| 6.14 | Food Assistance/Food Stamps | 6.14 ____ | ____ |
| 6.15 | Homemaker/Chore Services | 6.15 ____ | ____ |
| 6.16 | Cooking/Meals on Wheels | 6.16 ____ | ____ |
| 6.17 | Companion/Friend-Advocate Program | 6.17 ____ | ____ |
| 6.18 | Self Help/Support Groups | 6.18 ____ | ____ |
| 6.19 | Financial Management Assistance | 6.19 ____ | ____ |
| 6.20 | Community Support Services | 6.20 ____ | ____ |

LEVEL OF NEED

1 = NOT NEEDED AT ALL
2 = SLIGHT NEED
3 = MODERATE NEED
4 = STRONG NEED
5 = URGENT OR PRIMARY NEED
9 = DON'T KNOW

REASON FOR NOT RECEIVING

1 = NOT ELIGIBLE BY TYPE OR DEGREE OF DISABILITY
2 = NOT ELIGIBLE BECAUSE OF INCOME OR MEANS
3 = SERVICE IS TOO EXPENSIVE TO OBTAIN
4 = SERVICE IS NOT AVAILABLE IN THE AREA
5 = SERVICE THAT IS AVAILABLE IS NOT APPROPRIATE TO NEEDS OR PERSON DOESN'T LIKE THE SERVICE
6 = PERSON DID NOT KNOW THE SERVICE EXISTED
7 = ON A WAITING LIST OR AVAILABILITY IS LIMITED
8 = ANY OTHER REASON
9 = UNKNOWN
0 = CURRENTLY RECEIVING SERVICE

| | | | Level of Need | Reason not Receiving |
|---|---|---|---|---|
| 7.0 | TRANSPORTATION | | | |
| 7.1 | Transp'n to and from work, school, day activity | 7.1 | ____ | ____ |
| 7.2 | Transp'n to and from non-daily activities (e.g., medical appointments, shopping) | 7.2 | ____ | ____ |
| 7.3 | Transp'n for leisure time (weekdays) | 7.3 | ____ | ____ |
| 7.4 | Transp'n for leisure time (weekends) | 7.4 | ____ | ____ |
| 7.5 | Vehicle Modification | 7.5 | ____ | ____ |
| 7.6 | Transportation Training (driver's education, use of public transportation, etc.) | 7.6 | ____ | ____ |

For the items in the CAREGIVER SUPPORT SERVICES section, the caregiver should always be consulted. A caregiver is intended to mean someone other than the consumer. The questions are meant to be asked of a family member or other non-paid person.

| | | | | |
|---|---|---|---|---|
| 8.0 | CAREGIVER SUPPORT SERVICES | | | |
| 8.1 | Respite Care, In Home | 8.1 | ____ | ____ |
| 8.2 | Respite Care, Outside Home | 8.2 | ____ | ____ |
| 8.3 | Child Day Care | 8.3 | ____ | ____ |
| 8.4 | Homemaker/Chore Services | 8.4 | ____ | ____ |
| 8.5 | Behavior Management Assistance/Training | 8.5 | ____ | ____ |
| 8.6 | Family Counseling | 8.6 | ____ | ____ |
| 8.7 | Parent Training | 8.7 | ____ | ____ |
| 8.8 | Family Education | 8.8 | ____ | ____ |
| 8.9 | Genetic Screening and/or Counseling | 8.9 | ____ | ____ |
| 8.10 | Family Cash Assistance | 8.10 | ____ | ____ |
| 8.11 | Family Support Services (Other _____) | 8.11 | ____ | ____ |
| 8.12 | Adult Day Care | 8.12 | ____ | ____ |
| 8.13 | Family Support Group | 8.13 | ____ | ____ |

LEVEL OF NEED

1 = NOT NEEDED AT ALL
2 = SLIGHT NEED
3 = MODERATE NEED
4 = STRONG NEED
5 = URGENT OR PRIMARY NEED
9 = DON'T KNOW

REASON FOR NOT RECEIVING

1 = NOT ELIGIBLE BY TYPE OR DEGREE OF DISABILITY
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8 = ANY OTHER REASON
9 = UNKNOWN
0 = CURRENTLY RECEIVING SERVICE

| | | | Level of Need | Reason not Receiving |
|---|---|---|---|---|
| 9.0 | OTHER SERVICES | | | |
| 9.1 | Recreation/Leisure Services | 9.1 | ____ | ____ |
| 9.2 | _____(Specify) | 9.2 | ____ | ____ |
| 9.3 | _____(Specify) | 9.3 | ____ | ____ |

## THE CONSUMER EMPOWERMENT PROJECT

The Consumer Empowerment Project is a multi-year effort to identify, plan and implement a series of activities in Virginia that will (1) increase self advocacy among persons with disabilities, (2) build consumer group leadership, and (3) support and strengthen consumer groups in their efforts at advocacy.

1. **Self-Advocacy**

   - o development of self-advocacy materials
   - o self-advocacy training

2. **Leadership Development**

   - o surveys of leadership skills
   - o development of leadership training package
   - o cross-group training
   - o resource targeting for community-based groups
   - o development of an Executive Leadership Institute for advanced leadership training

3. **Strengthening Consumer Groups**

   - o coalition building
   - o materials on innovative programs
   - o membership marketing materials
   - o assistance with alternative (non-DD) sources of funding
   - o consultation and technical assistance

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